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An exploratory trial for examining effects of Self-Management Education Programme on patients with Chronic Obstructive Pulmonary Disease in Macau

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Declaration

I hereby declare that this thesis is my own work and has not been submitted for any other degree or professional qualification.

Wai I NG
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Abstract

Background: Respiratory disease has been one of the top three causes of deaths in Macau in the past decade. As one of the chronic respiratory diseases, chronic obstructive pulmonary disease (COPD) is incurable, but is preventable and treatable. COPD patients suffer from recurrent and progressive respiratory symptoms, and this impacts the health and well-being of patients. Self-management education programmes (SMEP) provide teaching and learning guidance for understanding COPD, emotional support and behaviour change needed to carry out disease-specific care in chronic patients. Evidence has demonstrated that SMEP can mediate a change in health-related behaviours, improve symptom control and the quality of life of COPD patients, with an associated reduction in health care utilization. However, SMEP has never been conducted in Macau, and experiences of providing any form of chronic care for COPD patients in this place is lacking.

Aims: This study aimed to explore the effects of a specifically designed self-management education programme on Stage II to IV COPD patients in Macau.

Design: The study was conducted as an exploratory randomized controlled trial in a mixed methods approach. Both illness perception and self-efficacy beliefs were adopted to formulate the theoretical framework. In the quantitative strand, the assessment of primary outcomes included illness perception, self-efficacy and inhaler technique. The secondary outcomes included pulmonary function, healthcare utilization and health-related quality of life. In the qualitative strand, focus groups were conducted to explore the subjective perception and experiences of self-management of COPD patients. Fifty one eligible COPD patients were recruited and allocated to experimental (26 patients) and control group (25 patients) by block randomization. A SMEP for COPD patients was developed and validated according to Medical Research Council (MRC) framework.

Results: Quantitative results indicated that the primary outcomes (illness perception, self-efficacy and inhaler technique) improved in the experimental group after the

SMEP. In relating to the secondary outcomes, days of hospitalization were reduced and symptom dimension of disease-specific health related quality of life (St. George Respiratory Questionnaire) improved. Qualitative findings identified the emergence of a core theme 'Essentiality' and five sub-themes 'Helplessness', 'Mutual involvement', 'Support', 'Control' and 'Beneficial', indicating perception and experiences of participants for self-management. These findings indicate a potential relationship of illness perception and self-efficacy in guiding COPD patients to adapt to health-related behaviour.

Discussion and Conclusion: This study has obtained evidence for supporting the proposed theoretical framework and expected experimental effect through employing the MRC guidelines. The study also confirms the estimates of recruitment for a definitive RCT, demonstrated readiness and positive impact in Macau COPD patients to receive self-management intervention, and SMEP as an acceptable and preferable mode of chronic care for COPD for the healthcare system of Macau.

Table of Content

Chapter One Introduction

1.1 Introduction

Respiratory disease has been one of the top three causes of deaths in Macau in the past decade. Chronic obstructive pulmonary disease (COPD) contributed to one of the top ten causes of mortalities (SSM, 2008a, SSM, 2011). As a chronic lung ailment, COPD is incurable, but is preventable and treatable (GOLD, 2013, ATS, 2004, NICE, 2011). It is believed that exposure to tobacco smoke is the major risk factor for COPD, while others include genetic factor or environmental exposures (NHLBI, 2009, NICE, 2011). Intriguingly, recent report indicated that gastro-oesophageal reflux may be associated with COPD, although such claim remains controversial (Pacheco-Galván et al., 2011, NHLBI, 2009b, NICE, 2011). Due to the marked increase in tobacco usage in developing countries and aging of the population, it is predicted that there will be an increased prevalence of COPD with associated morbidity and mortality in the coming decades (Boon and Davidson, 2006, Lopez et al., 2006, GOLD, 2008, GOLD, 2013, WHO, 2008). As a nursing professional with research interests in respiratory illnesses in Macau, I was interested to explore and develop an effective mode of care to prevent COPD patients in Macau from disease deterioration and to improve their overall quality of life.

1.2 Background of the study

1.2.1 COPD as a Research Target

Patients having COPD suffer from recurrent and progressive symptoms of coughing, sputum production, exertional dyspnoea and eventually respiratory failure. The progressive nature of the disease erodes the health and well-being of patients and imposes adverse effects, for instance, disability in their daily living. With COPD, individuals need to cope not only with the symptoms of their disease, but also with the multiple psychological, social, and physical problems associated with their condition. Preventing medical crises, managing crises that do occur, handling the prescribed treatment, controlling symptoms, and overcoming disabilities, stigma, social isolation and economic issues are all related to coping with COPD (Bourbeau,

2003). Some patients may cope very well and adapt to living with it, but for others, the chronicity of COPD can adversely affect their coping outcomes (Hwa and Lin, 2005), resulting in poorer quality of life and/or social dependency.

For the individual and the healthcare system to confront and relieve this burden, patients with COPD are increasingly being encouraged to be actively involved with the management of their own illness (Blackstock and Webster, 2007, Bourbeau and van der Palen, 2009, Bourbeau et al., 2004, Watson et al., 1997). Active participation is a strategy for formulating health behaviour which could buffer the chronicity impact of the illness on the patients, it thus helps the chronically ill patients to adapt more easily to this chronic condition and cope with the chronicity impact (Hwa and Lin, 2005). This health behaviour could be enhanced, for instance by a self-management programme that provides teaching and learning, guidance for health behaviour change, emotional support, and the skills needed to carry out medical regimens specific to the disease (Bourbeau, 2003). Self-management programmes were developed and implemented in the healthcare system in the West in the 1990's (Kaptein et al., 2009). Evidence has demonstrated that self-management interventions mediate a change in health-related behaviour, improve symptom control and the quality of life of COPD patients, with an associated reduction in health care utilization (Kaptein et al., 2009, Horne and Weinman, 2002, Kohler et al., 2002, Lau-Walker, 2006, Lorig et al., 2001).

1.2.2 COPD nursing in Macau

In Macau, the emphasis of healthcare service provision to COPD patients is mainly focused on acute management based on the stated mission of "Adequate treatment Prioritizing prevention" of the Health Bureau (SSM, 2012a) (Refer to Appendix 1). The COPD patients are provided adequate medical treatment and promotion for smoking cessation is the main prevention strategy for COPD (SSM, 2008b). The chronic care provision for COPD patients is limited in Macau and no COPD nursing-related studies or experiences have been reported in any papers or publications (SSM, 2002-2010, KWNC, 2002-2011). In the modern era of evidence

based medicine, there is room to explore the impact in this population. On the contrary, the management of these patients probably relies on the hospital's acute care service and this will burden the already stretched healthcare service; and this burden is an avoidable use of this service (AMN, 2009). Therefore, self-management intervention is identified as a potential approach for promoting the nursing care for Macau COPD patients as well as improving the overall quality of healthcare of Macau.

However, active self-management with the disease appears challenging to Macau patients who are mostly Chinese. It is because the Chinese patients were often found to exhibit poor health knowledge and skills in relation to their chronic disease and self-medication (Tian et al., 2011a, Yin et al., 2013). Evidence demonstrates that more Chinese patient choose to acquire knowledge on self-medication from TV advertisement than from physicians (Li, 2008). Thus, Chinese tend to undertake a passive engagement with healthcare. Instead of directly importing the Western mode of nursing care to local COPD patients in Macau, it is necessary to explore the feasibility, appropriateness and effectiveness of this approach before application. As an initiative study in Macau, I have adopted the Medical Research Council (MRC) guidelines (2008) and cognitive-behavioural theories for developing complex intervention, and employed a mixed methods approach for the design of the study. It aims to explore the impact of self-management education programme on patients with COPD in Macau, in relation to patients' subjective experiences, biomedical, behavioural and psychosocial aspects. The study placed particular emphasis on the facilitating effects of self-management intervention towards enhancing illness perception and self-efficacy beliefs of COPD patients, to initiate health behaviour changes and to improve the overall quality of life of these patients.

1.3 Importance of the study

Given the predicted impact of self-management education programme on COPD patients, this study informs the concrete benefits and weaknesses of this self-management intervention applying to the Macau population who are from a

different health system and of different culture. It will provide preliminary evidence that engaging patients with COPD in self-management has a mediating effect on self-beliefs. The study has also identified components for constructing a more effective and appropriate local care delivery mode for COPD patients in Macau and this can potentially be applicable to patients with other chronic illness. The findings and experiences derived from the study have also served as a very good foundation for a full randomized controlled trial (RCT). In the long run, it provides practical information for initiating a framework for developing a nursing care model for the chronically ill of the Chinese population in Macau.

1.4 Summary

COPD patients in Macau lack the supportive care for living effectively with their chronic condition, and self-management intervention has the potential to fill this health delivery gap. Therefore, this study aims to examine the effectiveness of this intervention on COPD patients in Macau with an integration of MRC guidelines and mixed methods design. These will be covered in eight chapters of this dissertation. Chapter one provides an introduction to the background and importance of the study. Chapter two will provide an overview of COPD in terms of its definition, diagnosis and clinical management. Chapter three will present a critical literature review of the background of self-management and its impact on COPD patients, followed by rationale for the development of the research questions. Chapter four will address the theoretical framework that combines illness perception and self-efficacy beliefs employed in the study. Chapter five will be divided into five sections to address the design of the study. Quantitative results and qualitative findings will be presented in chapters six and seven respectively. Chapter eight will provide an in-depth discussion of the findings and conclude with the implications and limitations of the study.

Chapter Two Overview of COPD

2.1 Introduction

This chapter gives an overview of COPD which is the condition of the target population in this study. Since COPD is a combined disease state, it does not have a unified definition, clinical diagnosis and classification. This issue will be addressed in this chapter. The prevalence of COPD and its associated problems in various populations will be followed. Lastly, patients with COPD require a comprehensive approach in clinical management and this will be covered with a special attention to self-management intervention in the last section of this chapter. The understanding of the background of COPD will help to identify the knowledge or care gap for enhancing the health status of these patients in Macau.

2.2 Background of COPD

2.2.1 Definition of COPD

According to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) and the American Thoracic Society (ATS), two professional respiratory medicine groups, COPD is defined as a preventable and treatable disease state characterized by persistent airflow limitation that is usually progressive and is associated with an abnormal or advanced chronic inflammatory response to noxious particles or gases in the airways and the lung (GOLD, 2013, ATS, 2004). Medical Research Council (MRC) refers COPD to:

> "*a group of long-term lung disease that includes chronic bronchitis and emphysema. It involves a narrowing of the airways that makes it harder for air to get in and out of the lungs*" (MRC, 2013).

Hence, COPD has also been called chronic obstructive airway disease (COAD) and chronic airway limitation (CAL). The airflow obstruction or limitation characteristic in COPD patients does not change markedly over several months (NICE, 2011). The chronic airflow limitation is caused by a mixture of pathophysiological alterations in the lung, such as small airway disease (Chronic bronchitis) and parenchymal

destruction (Emphysema) (GOLD, 2013). The clinical definition of chronic bronchitis is:

> "*chronic productive cough for 3 months in each of 2 successive years in a patient in whom other causes of productive chronic cough have been excluded* " (ATS, 2004).

Emphysema is

> "*defined pathologically as the presence of permanent enlargement of the airspaces distal to the terminal bronchioles, accompanied by destruction of their walls and without obvious fibrosis*" (NHLBI, 1985)

These two definitions reflect pathological alteration in the trachea and alverolar-capillary unit respectively. These pathophysiological alterations are caused by chronic inflammation of the airways which leads to membrane swelling and mucus secretion resulting in narrowing and changes in the airway structures. Destruction of the lung parenchyma, also by inflammatory processes, leads to the loss of alveolar attachments to the small airways and decreases lung elastic recoil. Consequently, the combined effect of these pathophysiological changes diminishes the ability of the airways to remain open during expiration and leads to progressive hyperinflation and decreased pulmonary compliance. This may result in respiratory failure and other complications such as cor pulmonale (Reid and Innes, 2010). The degree and pace of progression of airflow limitation and development of complication in COPD patients varies from person to person (GOLD, 2013, Reid and Innes, 2010).

In addition, COPD is expounded as a disease state that is accompanied by airway hyperactivity and may be partially reversible (Tierney et al., 2002). Thus, despite predominantly comprising of chronic obstructive bronchitis and emphysema, a small proportion of chronic asthma patients whose airway obstruction has become progressively less reversible over time coexist with COPD and chronic asthma was suggested to be included in COPD (Williams, 1993). Apart from pulmonary component, COPD also demonstrates systematic impact on an individual (Decramer et al., 2005). Cachexia is commonly found in severe cases of COPD. This is characterized by impaired nutrition, unexplained weight loss and loss of skeletal muscle mass and weakness. Evidence demonstrated a meaningful correlation

between low body weight and reduced survival rates in patients with COPD, regardless of lung function impairment (Decramer et al., 2005). In addition, COPD patients are more likely to have osteoporosis, depression, chronic anaemia and cardiovascular diseases (Boon and Davidson, 2006).

In summary, COPD is a heterogeneous disease state which bears the features of airway inflammation, airway hyperactivity, progressively and largely irreversibly destruction of airway structure and airway blockage. It includes emphysema, chronic bronchitis and chronic asthma. In addition, COPD patients may also suffer from systematic and extrapulmonary disorders. Therefore, we need to understand and keep updating the prevalence and stages of the disease so as to provide timely and adequate intervention and this will come next.

2.2.2 Epidemiology of COPD

COPD is a life-limiting lung disease of which the primary cause is tobacco smoke whether through direct use or second-hand exposure. A report from United States stated that COPD affects one out of five persons over the age of 45 (NHLBI, 2009a). Moreover, the number of people with COPD who do not know about it accounts for the same number formally diagnosed with COPD. In UK, It is estimated that more than two thirds of the three million people with COPD in the UK remain undiagnosed. They are probably left untreated and could potentially suffer from severe restriction in their lives (BLF, 2012). In China, the overall prevalence of COPD was 8.2% (of which 12.4% were male and 5.1% female) and approximately 65% of them were under-recognized or underdiagnosed (Zhong et al., 2007). It has caused more than three million deaths in 2005, equating to 5% of all deaths globally that year (WHO, 2012). It is also estimated to contribute to more to the global burden of disease in terms of disability-adjusted life years (DALYs) than other respiratory diseases such as asthma and tuberculosis (Aït-Khaled et al., 2001). Overall, COPD is currently the fourth leading cause of death in the world (WHO, 2008). In Macau, respiratory disease is the third top cause of all deaths in recent years, coming after neoplasms and diseases of the circulatory system (SSM, 2008a). Obstructive airway

disease, not including chronic bronchitis, ranged between the sixth to eighth top cause among all disease causes of death from 2004 to 2011 (SSM, 2009, SSM, 2011). However, World health statistics estimated that total deaths linked to COPD are projected to increase by more than 30% in the next 10 years if there is no effective intervention to cut risks. Then, COPD may become the third leading cause of death in 2030 while deaths are predicted to decline in other communicable diseases (WHO, 2008).

2.2.3 Clinical Diagnosis

Emphysema and chronic bronchitis are the two main diseases comprising COPD. COPD patients usually demonstrate signs and symptoms caused by airway hypersensitivity, inflammation and narrowing, and eventually as the disease progresses they may develop problems with gas exchange and finally developing respiratory failure. A clinical diagnosis of COPD should be considered in any patient aged over 40 who presents with progressive or exertional dyspnoea, chronic cough or sputum production, and/or a history of exposure to risk factors for the disease. Spirometry serves as the gold standard and objective approach to make the diagnosis. The presence of a postbronchodilator FEV_1/FVC (Forced Expiratory Volume in the first second / Forced Vital Capacity) < 0.70 confirms the presence of airflow limitation that is not fully reversible (ATS, 2004, GOLD, 2013, Reid and Innes, 2010). In some patients with chronic asthma, it is impossible to completely distinguish COPD from asthma using current testing techniques, and both conditions are assumed to be coexistent in some patients (GOLD, 2013). In the aspect of differential diagnosis, patients with asthma, congestive heart failure, lung carcinoma, bronchiectasis, pulmonary tuberculosis, bronchiolitis obliterans and interstitial lung diseases may also present with shortness of breath or symptoms similar to COPD, but they should not address poorly irreversible airflow.

2.2.4 Clinical Classification

The spirometric classification of COPD launched by GOLD provides a referencing

clinical criterion for classifying the severity of COPD. GOLD launched the first spirometric classification of COPD in 2001 and classified the spirometric severity of COPD into 5 categories - From Stage 0 (At Risk) to Stage IV (Very Severe) (GOLD, 2004). In 2008, GOLD updated the classification criteria by leaving out the first category (Stage 0) and keeping Stages I - IV (Mild to Very Severe). Details are shown in Table 1. It claimed that there was incomplete evidence for individuals who met the definition of 'At Risk' necessarily progress on to Stage I (Mild COPD) and this 2008 version has been used since then (GOLD, 2008, GOLD, 2013). However, ATS who worked with the European Respiratory Society (ERS), keeps the five stages of spirometric classification and has not been updated since 2004 (ATS, 2004).

In reality, there are diverse preferences among physicians about the use of external criteria in making a diagnosis. For instance, in Macau, some clinicians prefer to diagnose COPD based on their clinical expertise and spirometry is not routinely used. Nevertheless, the GOLD classification is popular and widely used in classifying participants in surveys and comparing results in experimental researches (Lemmens et al., 2010, Rootmensen et al., 2008, Chen et al., 2008a). GOLD (2013) reminded that there is a weak correlation between pulmonary function, symptoms and impairment of a patient's health-related quality of life (HRQoL).

The severity of COPD can be identified in terms of both spirometry findings and clinical presentations of the patients as illustrated below.

Stage I : Mild COPD – Symptoms of chronic cough and sputum production may be present, but not always. At this stage, the individual is usually unaware that his or her lung function is abnormal.

Stage II : Moderate COPD – Shortness of breath typically developing on exertion and cough and sputum production sometimes also present. Patients at this stage typically seek medical attention because of chronic respiratory symptoms or an exacerbation of their disease.

Stage III : Severe COPD – Greater shortness of breath, reduced exercise capacity, fatigue, and repeated exacerbations that almost always impacts on patients' quality of life.

Stage IV : Very Severe COPD – The presence of respiratory failure may also lead to effects on the heart such as cor pulmonale. At this stage, quality of life of the patients is very appreciably impaired and exacerbations may be life threatening.

Table 1. Comparison of the Spirometric Classification of COPD severity based on Post-Bronchodilator FEV_1 by GOLD between versions in 2001 and 2008.

Stage	Spirometric results based on Post-Bronchodilator FEV_1	
	2001	2008
Stage 0 : At Risk	Chronic cough and sputum production; lung function is still normal	---
	In patients with $FEV_1/FVC < 0.70$	
Stage I : Mild	$FEV_1 \geq 80\%$ predicted	$FEV_1 \geq 80\%$ predicted
Stage II : Moderate	$50\% \leq FEV_1 < 80\%$ predicted	$50\% \leq FEV_1 < 80\%$ predicted
Stage III : Severe	$30\% \leq FEV_1 < 50\%$ predicted	$30\% \leq FEV_1 < 50\%$ predicted
Stage IV : Very severe	$FEV_1 < 30\%$ predicted or $FEV_1 < 50\%$ predicted plus chronic respiratory failure	$FEV_1 < 30\%$ predicted or $FEV_1 < 50\%$ predicted plus chronic respiratory failure

Source: 1) (GOLD, 2004) ; 2) (GOLD, 2008)

2.3 Clinical Management of COPD

Presently, there is no cure for COPD, however, it is preventable and treatable (GOLD, 2013, ATS, 2004, Reid and Innes, 2010). Patients should be identified as early in the course of the disease as possible and definitely before the late stage of the illness when exertional dyspnoea or disability is substantial. Therefore, management of patients with COPD is focused on two components: (1) prevention - assessing and monitoring disease and reducing risk factors, (2) treatment – managing stable COPD and exacerbations (GOLD, 2008, ATS, 2004, GOLD, 2013). Prevention involves public health strategy in combating tobacco use, improving air quality, vaccination and detection of early cases. Conventional treatment for COPD usually includes pharmacotherapies, non-pharmacotherapies and surgery (Reid and Innes, 2010, NHLBI, 2006). Advances in therapies have improved survival for COPD patients (NIH, 2009). Pharmacologic therapy for COPD includes prescribing bronchodilators, corticosteroids and antibiotics in accordance to individualized assessment with the

goal of reducing symptoms, the frequency and severity of exacerbations, and improving health status and exercise tolerance. The treatment is usually given by oral tablets or by inhaled route. Common inhaler devices are metered-dose inhaler (MDI), dry powder inhaler (DPI) and nebulizer. MDI usage requires patients to coordinate with the dose initiation of the device. It can be used alone or combined with a spacer device or aerochamber to overcome coordination problems and improve lower airway deposition. DPI includes turbuhaler, accuhaler and handihaler, and they are breath-induced in usage. Nebulized therapy is usually given to patients of severely overinflated and very low inspiratory flow rate.

Non-pharmacologic therapies includes pulmonary rehabilitation, oxygen therapy and ventilator support. The principal goals of pulmonary rehabilitation are to reduce symptoms, improve quality of life, and increase physical and emotional participation in everyday activities (GOLD, 2013). Pulmonary rehabilitation generally refers to a comprehensive programme which consists of exercise training, smoking cessation, nutrition counseling and education. Exercise training ranges from inspiratory muscle training to endurance training (for instances, the former being pursed-lips breathing, maximum sustained voluntary ventilation, inspiratory resistive breathing, and threshold loading, and the latter being treadmill exercise, bicycle ergometry) with the aims to regulate the breathing pattern of the patients and to improve their exercise tolerance (Grassino, 1989, Reid and Samrai, 1995, GOLD, 2013). In the practical implementation of pulmonary rehabilitation, it is ideally run by a multidisciplinary team which comprises respiratory doctor, respiratory nurse, respiratory physiotherapist, occupational therapist, dietician, smoking cessation adviser, social worker, and pharmacist (Man et al., 2004). However in reality, it depends on the local availability, cost and administrative policies. In general, nurse or/and physiotherapist are two main professionals who provide it, yet in their health education the nurses' role is often limited to delivering smoking cessation, nutrition counseling, education and light exercise training (for instances, pursed-lips breathing and upper limb exercises) (Watson et al., 1997, Littlejohns et al., 1991, Lacasse et al., 1996). When both pharmacological and non-pharmacological approaches are unsatisfactory and the patients fulfill the indication for undergoing surgery, bullectomy or lung volume

reduction surgery or lung transplantation can be alternative options (GOLD, 2013).

In this case, corresponding nursing management of patients with COPD has thus been evolving from simply one-way patient education to dynamic patient self-management education and lately with a collaborative chronic care model to respond to the comprehensive needs of COPD patients (Kaptein et al., 2009). Providing patient education to improve patients' knowledge is necessary, although knowledge improvement about the disease provides no guarantee of improvements in illness behaviour or self-care, or most importantly in well-being (Bourbeau et al., 2004, Bourbeau and van der Palen, 2009, Kaptein et al., 2009). To improve the health of chronically ill patients, improving knowledge by patient education alone was demonstrated to be rarely successful and together with behavioural modification formulating behavioural-oriented interventions (i.e. self-management education) have been found to be consistently more successful at enhancing the clinical course of chronic disease (Blackstock and Webster, 2007, Bourbeau et al., 2004, Adams et al., 2007). Furthermore, development of a more advanced care delivery mode, called chronic care model has been proposed in the past decade. It incorporates health care delivery system design, decision support, and clinical information systems in additional to nurse-led self-management education or multidisciplinary pulmonary rehabilitation, resulting in a desirable patient care environment (Adams et al., 2007). However, chronic care model is not justified to be introduced to Macau. It is because this model demands multi-disciplinary and systematic effort. Its requirement for setting up is likely beyond the local preparedness and the pace of healthcare development of Macau where respiratory specialized nursing has not yet been developed for managing COPD patients. Also, introduction of chronic care model goes beyond the scope of a nursing study. Therefore, to be practical, self-management education is more feasible to be introduced to the COPD patients in Macau.

2.4 Summary

COPD is an incurable obstructive airway disease state which broadly includes emphysema, chronic bronchitis and chronic asthma. It is one of the top causes of death regionally, nationally and worldwide, and global health prediction is claimed to cause more deaths. It can place a tremendous burden for the individual, family, society as well as the country; this is due to the progressive disability and healthcare dependence associated with the development of the disease. Importantly, COPD is preventable and treatable. There is standard reference and spirometric classification for clinical diagnosis and disease severity determination respectively. Clinical management of COPD patients comprises components of prevention and treatment with an integration of pharmacotherapies and non-pharmacotherapies. Much evidence indicates that nurses could play a significant role in equipping the patients to live with their chronic condition by self-managing their disease, in terms of self-management education programme (SMEP). As a comparatively new approach, the effect of SMEP on COPD patients in Macau is yet to be studied and remains unknown to this population. Therefore, a critical literature review of the background of self-management intervention and relevant experiences in Macau will be presented in the following chapter.

Chapter Three Literature Review

- Self-management and COPD patients

3.1 Introduction

Self-management education or self-management education programme is an approach that evolved throughout the 1990s in the West (Kaptein et al., 2009). It is an advancement of the healthcare for the chronically ill whose conditions are multiply determined, and the traditional acute care mode could no more have satisfied the health needs of these patients (Kaptein et al., 2009, Oleary, 1985). To implement and evaluate a self-management intervention for COPD patients in Macau demands a thorough assessment of corresponding theories and experiences so as to get a full picture of the research subjects and context. The aims of this chapter, therefore, are to define self-management and self-management intervention, to review the impact of self-management intervention on COPD patients and the common outcome evaluations for this intervention. This critical review of literatures will be concluded at the end of the chapter outlining the potential for eliciting a theoretical framework within this study.

3.2 Literature searching strategy

Literature has been identified from searches on Medline, CINAHL, the Cochrane library, PsycINFO, EMBASE, Google scholar, hand searched local health-related journals, websites of professional group and authorities, and doctoral dissertation for the years 1970 to 2013 (March). Keywords used in literature searching included COPD, chronic obstructive pulmonary disease, chronic obstructive airway disease, patient education, patient self-management, self-management, self-care, chronic care, self-management education, self-management programme, disease-management. From these search results articles written in English or Chinese are selected. Bibliographies of the retrieved articles were also reviewed for additional papers.

3.3 Definition of Self-management

Self-management is defined as:

> "*the active participation of the patient in the treatment of the disease based on sufficient coping behaviour, compliance with inhaled medication, attention to changes in the severity of the disease, and adequate inhalation technique*" (Worth and Dhein, 2004, P. 267).

Self-management is also described as:

> **"***a set of skilled behaviours and refers to the various tasks that a person carries out for management of their condition"* (Bourbeau et al., 2004, P. 271).

It is obvious that self-management comprises much more than patient education or just aiming at making patients more knowledgeable. Self-management actually involves patients participating actively in their care by integrating skills to manage their daily life and acute exacerbation by means of engaging health behaviour or carrying out medical regimens. To actualize self-management in the patient, a relevant education programme has to be present in the process of care. Such an education programme is usually called self-management education, self-management programme or self-management education programme, and these names are usually used interchangeably. As defined by Bourbeau (2003), self-management education programme applies to:

> "*training that integrated specific skills for patients to control their disease and live functional lives. The programme could include education about recognition of an acute exacerbation and action to be taken, as well as periodic home visits and telephone calls provided by a health professional*" (Bourbeau, 2003, P. 313).

In this dissertation, the term 'self-management education programme (SMEP)' is used. Each of the above approaches incorporates cognitive elements such as promoting positive self-talk with an attempt to challenge irrational beliefs about the adverse effects of treatment, and also includes managing skills and behavioural elements such as goal-setting, a behavioural contract and training in contingency management (Kaplan et al., 1984).

3.4 Self-management Education Programme (SMEP)

3.4.1 Components of SMEP

SMEP aims at health behaviour changes, and the relevant behaviour modification implies the appropriate use of many disease-related skills (Bourbeau et al., 2004). SMEP usually involves two categories: COPD education and self-treatment guidelines (i.e. an action plan) (Effing *et al* 2009). The COPD education includes knowledge of COPD and disease-specific health behaviours. The action plan which is self-treatment guidelines is a written plan which helps an individual recognize a deterioration in their symptoms and to initiate changes to treatment early and reduce the impact of the exacerbation (Walters et al., 2010). Evidence indicated that a multi-component self-management education programme can have an impact on the health status of patients with COPD (Bourbeau, 2003). Referring to GOLD guidelines (2013), the combination of the components in an education programme for COPD varies according to different stages of the disease. Information and advice about reducing risk factors is regarded as essential at all stages. In addition to that:

Stage I Mild COPD to Stage III Severe COPD

- Information about the nature of COPD
- Instruction on how to use inhalers and other treatments
- Recognition and treatment of exacerbations
- Strategies for minimizing dyspnoea

For Stage IV Very Severe COPD

- All of the above topics
- Information about complications
- Instruction on using oxygen treatment
- Discussion of advance directives and end-of-life decisions.

Systematic reviews by Bourbeau (2003), Monninkhof et al. (2003) and Effing et al. (2007) revealed that SMEP empirically includes interventions such as teaching about the basic anatomy and physiology of the lungs and in relation to COPD, smoking

cessation, improving exercise, nutrition, self-treatment of COPD exacerbations or action plan, inhalation technique, stress relaxation technique, controlling breathing, energy conservation, education on coping with activities of daily living or community services, or a combination of these various elements. A patient who incorporates these self-management elements should integrate them in their everyday lives by considering their interrelationship and implementing appropriate changes in a variety of circumstances (Bandura, 1989, Searle et al., 2007).

3.4.2 SMEP in Clinical Practice

SMEP was provided in group or individual sessions by allied professionals from the forms: written, verbal, visual and audio (Effing et al., 2007). Programme material such as booklets was provided to the patients for reading (Bourbeau, 2003). In the group sessions, four to six participants were advised, as a small group arouses more interaction and involvement of the participants (Worth and Dhein, 2004, Kara and Aşti, 2004). Effing et al.(2007) and Monninkhof et al. 's (2003) systematic reviews revealed that the follow-up time of COPD SMEP studies ranged from two months to twelve, with one study also evaluating hospital admission after 24 months. It was also viewed that six monthly follow-up might be too short a duration to assess significant effects of self-management interventions on HRQOL of COPD patients (Rootmensen et al., 2008). However, the majority of studies took a six-month follow-up period (Coultas et al., 2005, Effing et al., 2007, Monninkhof et al., 2003). A wide variety of outcome measures were used to evaluate the effectiveness of SMEP. The next section deals with the impact of self-management and will review the potential measurements for assessment.

3.5 Impact of Self-management intervention on COPD patients and relevant Assessment

Various meta-analyses, review articles, randomised trials and observational studies provide substantial evidence that programmes providing self-management education are associated with improved outcomes ranging from the mastery of a particular skill

to various dimensions of the well-being of the COPD patients. (Lemmens et al., 2009, Effing et al., 2007). These outcomes include biomedical aspects (symptom control, frequency of exacerbations), health-related behaviour formation or behaviour change (proper inhalation skills or inhaler usage, appropriate medication use), self-belief (illness perception and self-efficacy), health-related quality of life (disease-specific health related quality of life) and healthcare utilization (hospital admission, hospital stay, outpatient visits, emergency room visits, general practitioner visits). However, SMEP is ineffective and does not show improvement in some indicators, for instance pulmonary function namely FEV_1, FEV_1/FVC and generic HRQoL (Effing et al., 2007, Watson et al., 1997, Lemmens et al., 2009). Exploration of empirical studies and relevant measures for assessing the outcomes in COPD follows in the next section.

3.5.1 Biomedical outcomes

The most important goal of self-management in COPD patients is to manage symptoms such as dyspnoea and exacerbations, anticipating that an approach from the patient may reduce the need to engage emergency consultation from healthcare services. In terms of symptom control, a significant reduction in dyspnoea measured with the BORG-scale or MRC was observed in COPD patients after receiving SMEP (Effing et al., 2007, Lemmens et al., 2010). Moreover, SMEP can significantly reduce exacerbations in COPD patients compared with the control group (Rootmensen et al., 2008, Worth and Dhein, 2004). In Rootmensen et al.'s (2008) study, patients in the group engaging in self-management eventually suffered from 1.5 exacerbations per 1,000 observation days while the incidence rate in the control group was 3.6 per 1,000 observation days. In that study, exacerbation was defined as worsening of respiratory symptoms that required treatment with oral steroids as judged and prescribed by general practitioner or pulmonary physician (Rootmensen et al., 2008).

The benefits of SMEP are independent of any effect on pulmonary function (at least in terms of FEV_1 or VC). The majority of studies have shown that the beneficial

effects of SMEP are not accompanied by any apparent improvement in pulmonary function in terms of bettering FEV_1 and FEV_1/FVC (Lemmens et al., 2009, Watson et al., 1997, Effing et al., 2007); but this may be due to the irreversible and progressive nature of COPD. Moreover, a considerable number of studies have found that pulmonary function test results neither show any strong correlation with health-related quality of life nor predict reduced quality of life of COPD patients (Yohannes et al., 1998, Kaptein et al., 2009, Stallberg et al., 2009). Thus, measurements of FEV_1 and FEV_1/FVC can reliably monitor any deterioration in respiratory function occurring during the course of the SMEP, but they may not be suitable to be the primary outcome of SMEP study.

3.5.2 Health-related behaviour formation or behaviour change

The inhaler is the main device for COPD patients to receive bronchodilators and corticosteroids and these medications form the major treatment regimen of these population. However, not all patients could have received an introduction into correct usage of their inhalation medication (Hämmerlein et al., 2011). A substantial proportion of inhaler users made at least one essential error in their inhalation technique when inhaling medication (Hesselink et al., 2001, Hämmerlein et al., 2011), this happened more on those using MDI than DPI (Molimard et al., 2003, Hardwell et al., 2011). Patient using MDI had the highest rate of incorrect handling among all inhalers, indicating that the majority of patients using MDI were unable to use it correctly (Khassawneh et al., 2008, Hilton, 1990). On the other hand, some studies demonstrated no significant dependencies on inhaler devices in the handling of inhalation technique (Hämmerlein et al., 2011, Roy et al., 2011). However, evidence shows that an improvement in inhalation technique and a reduction of more than 50% in the need of rescue medication in COPD patients when they are taught proper medication use (Gallefoss, 2004, Lemmens et al., 2009, Roy et al., 2011). In addition, DPI use remained significantly associated with higher rates of adherence (Roy et al., 2011). Proper inhaler technique and adherence may consequently improve control of COPD but also allow dose reduction in the long run (Hesselink et al., 2001). Moreover, repeated instruction on inhalation techniques was found to contribute to

adherence to inhalation therapy through decreasing intentional non-adherence (Takemura et al., 2010). Watson et al. (1997) found that SMEP also produced behaviour change in the interventional group in terms of more antibiotics usage when they had respiratory infections.

3.5.3 Self-belief

Theoretically, adherence to self managing and disease managing was associated with the specific illness and treatment beliefs of the patients (Horne and Weinman, 2002). Converging evidence demonstrated that SMEP can impact positively on either illness perception or self-efficacy which influences and mediates the change in health-related behaviours, symptom control, quality of life and health care utilization. (Horne and Weinman, 2002, Kaptein et al., 2009, Kohler et al., 2002, Lau-Walker, 2006, Lorig et al., 2001). When SMEP was introduced to the Chinese population with chronic illness in Siu and colleagues' (2007) study in Hong Kong, the team demonstrated significantly higher self-efficacy in the participants in managing their illness by means of more cognitive methods used to manage pain and symptoms, and felt more energetic than the non-educated patients.

Patients in self-management schemes also expressed feeling "much safer" or "safer" and higher satisfaction in living with their illness (Gallefoss, 2004, Lemmens et al., 2009). Findings echoed that the stronger the patients' feelings of capability to manage functional activities, the less functional impairment they feel (Kohler et al., 2002). Self-belief outcomes can directly reflect the 'product' of the education in terms of cognition and behaviour change.

3.5.4 Health-related quality of life

Health-related quality of life (HRQoL) refers to a multi-dimensional construct which contains different health state items that relate to symptoms, impairments, functional status, and emotional domains affected by an illness and its consequent therapy as

perceived by the patient (Chatterji et al., 2002, Smith, 2008). It has become, in chronic care, a welcome measure of health outcomes in addition to survival rates, duration or severity of disease, mortality rate and others. In regard of HRQoL of COPD patients, both young and old COPD patients were found to have significant impairment of HRQoL in comparison to normative population values (Alonso et al., 1998, Desikan et al., 2002, Stallberg et al., 2009).

Tam *et al.* (2007) also found that the HRQoL of COPD patients in Macau was lower than the norm of the population in Shanghai (Tam et al., 2007). These findings reflect a significant impact of COPD on patients' lives and that they are living with a lower quality of life than the general population. Nonetheless, there is controversy regarding whether or not SMEP can improve quality of life in COPD patients. Some posit that self-management by COPD patients is essential to achieve optimal quality of life (Bourbeau and van der Palen, 2009, Warwick et al., 2010). On the contrary, inconclusive results were observed in systematic reviews and randomized trials for improvements in health-related quality of life of COPD patients who either had self-care education or self-management plans when compared with patients without either (Coultas et al., 2005, Rootmensen et al., 2008, Watson et al., 1997, Effing et al., 2007, Adams et al., 2007, Monninkhof et al., 2003, Bucknall et al., 2012, Lemmens et al., 2010). Alternatively, a two-year longitudinal follow up of the effects of SMEP in Lorig's (2001) study found that participants did not show deterioration in any other health state as one would otherwise expect during that period of time (Lorig et al., 2001). Self-management may thus in some way promote the maintenance of health in COPD patients. Blackstock and Webster (2007) specifically emphasized that there was a tendency towards HRQoL improvement if patients were assigned to disease-specific self-management interventions. Hence, health-related quality of life improvement should be the ultimate goal of self-management coming after the establishment of self-management skills and self-belief (Bourbeau and van der Palen, 2009).

There are three main types of HRQoL measures used for assessing HRQoL of patients in healthcare setting, namely global QoL, generic QoL and disease-specific QoL

questionnaires (Smith, 2008). In regard to COPD, generic and disease-specific measures appear to be amongst the most widely used in clinical and research activities (Lemmens et al., 2009, Doll and Miravitlles, 2005). The generic health-related instruments include the EurolQol five-dimension questionnaire (EQ-5D), the Medical outcomes study 36-item short form health survey (SF-36), the Sickness impact Profile (SIP), the measure your medical outcome profile (MYMOP), the Medical outcomes study 6-item general health survey (MOS-6A), the Nottingham health profile (NHP), etc. (Doll and Miravitlles, 2005). Among them, SF-36 is one of the most commonly used generic instrument for comparing the measuring properties of the disease-related QoL measurement tool (Alonso et al., 1998, Stallberg et al., 2009).

The well-established respiratory specific disease-related QoL measurements are the St George Respiratory Questionnaire (SGRQ), the Clinical COPD Questionnaire (CCQ), the Chronic Respiratory Disease Questionnaire (CRQ), the Breathing Problems Questionnaire (BPQ), and the Airway Questionnaire (AQ 20/30). SGRQ is the most popular scale used in studies in Europe and America and occasionally in Asia (Alonso et al., 1998, Alemayehu et al., 2002, Desikan et al., 2002, Doll and Miravitlles, 2005, Lemmens et al., 2009, Stallberg et al., 2009, Lei et al., 2007, Lu et al., 2007, Mölken et al., 1999, Jones et al., 1991). In these studies, it is used as a standard tool to compare newly proposed questionnaires, to compare measurements of health between patient populations and as a strategy to monitor the outcomes of clinical interventions.

3.5.5 Healthcare utilization

COPD patients who have participated in SMEP appear to reduce visits to their general practitioner, number of outpatient visits as well as hospital admissions. In a twelve-month follow-up after patient education and self-management plan, educated COPD patients paid approximately five times less visits to their general practitioners than non-educated COPD patients (73% versus 15%, $P<0.001$). The reduction of the need for short-acting B2-agonist inhalations as rescue medication may keep a greater proportion of patients independent of their GPs (Gallefoss, 2004, Gallefoss and

Bakke, 1999). Moreover, SMEP was also associated with significant reduction in hospital admission or hospital days (Lorig et al., 2001, Worth and Dhein, 2004, Effing et al., 2007). The reduction equated to at least one hospital admission less among patients receiving SMEP compared to those receiving usual care (Effing et al., 2007, Lorig et al., 2001, Worth and Dhein, 2004). In contrast, another review demonstrated that SMEP itself did not improve hospitalizations or emergency visits, in patients with COPD (Adams et al., 2007) Thus, the impact of SMEP on the reduction of healthcare utilization is clearly possible, however, it may not always be the case.

3.6 Self-management Intervention in Macau

To explore the experiences of self-management or nursing care for COPD patients in Macau, literature searching on Medline, CINAH and two major health-related journals of Macau for the years 2001 to 2012 (December) was conducted by using key words including Macau, COPD, COAD, chronic obstructive pulmonary disease, chronic obstructive airway disease, chronic bronchitis, emphysema, disease-management, self-management, chronic illness (SSM, 2002-2010, KWNC, 2002-2011). Of the nine COPD-related papers found, however, none was related to nursing care for these patients. This implies either a lack of follow up care or inconclusive effects of self-management interventions for COPD patients in Macau. There is an absence of experience for both nurses and the COPD patients in Macau in participating in any continuous care promoting activity.

In Macau, over 90% of the residents are Chinese (DSEC, 2011). Chinese patients generally demonstrate inadequate health knowledge and behaviour regardless of their education (Tian et al., 2011a, Yin et al., 2013, Tian et al., 2011b). They preferably adopt a ‘convenient’ approach in promoting their own health as TV advertisement and health history of family members and friends were found to be their main source of the knowledge on disease control or treatment management (Tian et al., 2011a, Li, 2008). Therefore, Macau Chinese may probably be accustomed to passive

engagement with their disease management. However, SMEP requires them to shift their role to cooperating with health professionals and to being active participants in disease management, thus presenting challenges to the success of the intervention. Therefore, I initiated this study to fill this knowledge gap. Instead of directly importing the Western mode of nursing care into local COPD patient care in Macau, it is necessary to explore the feasibility, appropriateness and effectiveness of SMEP to a different population of different culture.

3.7 Research Questions

1) Could self-management interventions developed in the West have positive effects on COPD patients in Macau?
2) How do COPD patients in Macau perceive and adapt to a self-management approach?

3.8 Summary

This critical review of the literatures has demonstrated the development of SMEP in COPD care from an international perspective. A knowledge gap of the feasibility and effectiveness of SMEP for COPD patients in Macau is identified and relevant research questions are raised. On the other hand, pulmonary function, health utilization and quality of life are common measurements targeted to reflect the effectiveness of SMEP on patients with COPD or on other chronic illnesses. However, due to their inconsistency and time-consuming nature for achieving significant improvement in an individual's well-being, these outcomes are more likely to be the ultimate goals rather than primary goals of SMEP. In this case, the core goals of SMEP should anticipate converting the taught knowledge and skills into permanent beliefs and behaviour among the COPD patients before attaining the ultimate goals. Then the questions arise: what are the driving forces for the knowledge and skills of establishing health behaviour, how can one accept, utilise and integrate the COPD knowledge and self-treatment guidelines into daily living? Illness perception and self-efficacy are identified in bridging the cognitive-behavioural dynamic since they are two important conceptual determinants in constructing and maintaining behaviour through the understanding of one's thinking (Baum et al., 1984, Leventhal et al., 2008, Bandura, 1986, Bandura, 2004). The focus and the interrelationship in developing self-management behaviour in COPD patients are addressed in the theoretical framework which will be delivered in the following chapter.

Chapter Four Theoretical Framework of the Study

4.1 Introduction

There are many theories that try to bridge the divide between knowledge and action and the beliefs of self-perception and self-efficacy are two of them. Intriguingly, these two theories may potentially be effective in different but inter-related ways in enabling and sustaining an individual's control and influence over a long-term condition, (for example, in chronic disease management). Engaging in self-management necessarily requires the receiver (patient) to both understand and put into practice what has been explained (Bourbeau et al., 2004). The actualization of self-management is thus influenced by the patient's degree of understanding and of the capability to engage in self-management (Bourbeau et al., 2004, Bourbeau and van der Palen, 2009). Both theories of self perception and self-efficacy argue that when patients confront change, (for instance, in adaption to self-management), their existing beliefs on representation and perception of illness, cost and benefits of the change, and capability of behavioural change are being confronted (Bandura, 2004, Leventhal et al., 2008). So, although theories drive one's cognitive processing to seek an appropriate response, illness perception however is more likely to serve the cognitive belief of patients, while self-efficacy serves their efficacy-belief, they are different in scopes but share a mutual pathway to behavioural change (Lau-Walker, 2006). Here, the concepts of illness perception and self-efficacy are taken into account as the mediational influences of SMEP in achieving cognitive and behavioural change in patients with COPD. In this section, both concepts of illness perception and self-efficacy are examined critically to delineate their underlying theories and to explain their interrelationship in contributing to SMEP and formulating self-management behaviours in COPD patients.

4.2 Illness Perception

Illness perception refers to how patients create their own models or representations of their illness (Weinman et al., 1996). It is the core idea stemming from the self-regulation model of Leventhal and colleagues, who proposed that patients construct a representation of their experience with their illness and this, in turn,

determines their coping responses (Baum et al., 1984). The illness representation is derived from the patient's 'lay' beliefs and cumulative understanding about their illness and previous experiences, but when they are integrated with external information and existing schemata (the normative guidelines that people hold), they are interpreted into new representations. These interpretations are used to plan coping procedures or behaviour and to select action plans and outcomes (Hale et al., 2007, Weinman and Petrie, 1997). This can explain why people posit their condition and display differing emotional responses despite sharing the same diagnosis or equivalent severity of illness. The representation bears five components. These are:

1) Identity - labelling of the symptoms;
2) Cause - beliefs about the etiology of the illness;
3) Timeline - beliefs about how long the illness may last;
4) Consequences - beliefs about its consequences;
5) Curability / Controlability - belief about whether the illness can be cured or controlled.

These components can interact with each other, for instance, if a patient conceives his condition as genetically born (Identity), he is more likely to create a representation of his condition as long-lasting (timeline) or incurable (curability/ controllability). These representations develop as soon as patients become aware of their initial symptoms and are subjected to change with disease progression, emergent symptoms and treatment response (Weinman et al., 1996). These representations hence reflect the cognitive and emotional response of patients to their symptoms and illness. However, these representations are possibly affected by systematic cognitive and emotional biases employed by patients who may positively appraise an incurable condition, resulting in various patterns of health behaviour and variation in compliance with treatment (Weinman and Petrie, 1997). Due to the effect of patients' self representation of their illness on their coping, an understanding of patients' illness perceptions and intervention influencing patients' interpretations are essential for effective patient management.

4.3 Self-Efficacy

Self-efficacy is conceptualized as the cognitive processing of diverse sources of information conveyed by the direct and mediated experiences of an individual. It was first introduced by Albert Bandura in 1977, who proposed that personal efficacy is a self-referent thought in psychosocial functioning that mediates the relationship between acquisition of knowledge and performance of response patterns, meaning that it bridges the gap between knowledge and behaviour (Bandura, 1986, Bandura, 1977). Self-efficacy plays a central and explanatory role for analyzing and predicting the behavioural change of an individual (Bandura, 1977, Bandura, 2004, Warwick et al., 2010, Wong et al., 2005). In a self-efficacy approach, outcome expectations and efficacy expectations are the main constructs of the theory (as shown in Figure 1).

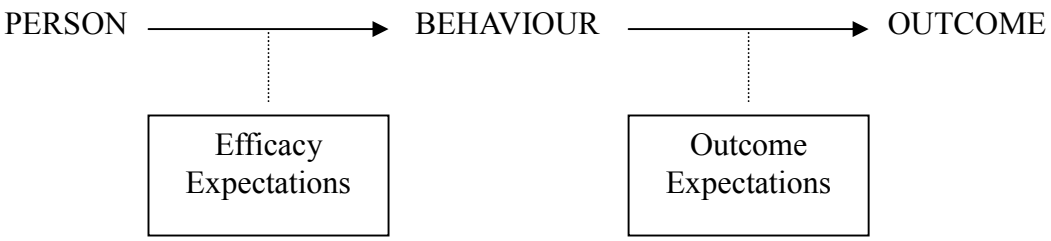


Figure 1. Diagrammatic representation of the difference between efficacy expectations and outcome expectations (as cited in Bandura 1977)

In outcome expectation, cognitive processes play a prominent role in the acquisition and retention of new behaviour patterns through learning from previously response consequences. Through self-corrective adjustments based on informative feedback from performance, previously response consequences serve as an inarticulated way of informing performers what they must do to gain beneficial outcomes and to avoid unfavourable ones. Another construct, efficacy expectation, is either the conviction that one can successfully execute the behaviour required to produce the outcomes or one's judgement of his/her capabilities to execute given levels of performances (Bandura, 1977, Bandura, 1986, Bandura, 2004). Thus, how one acts or behaves depends largely on one's self-appraisal of efficacy. Positive appraisal of personal efficacy influences the choice of behavioral settings, and when combined with positive outcome expectations, it can affect responding effort and persistence of that

behaviour (Bandura, 1977, Bandura, 1986, Bandura, 2004). To illustrate this, if COPD patients presume that they are capable of mastering self-management (efficacy expectation) and that adopting self-management strategies are good for their health (outcome expectation), they would be more likely to initiate and persist with self-management strategies. Conversely, if they judge self-management exceeds their capabilities (for instance, to implement an action plan) even if they know it is good, they may also avoid putting a self-management plan into practice. Previous findings have shown that behaviour is mediated by expectations and so were found to be consistent with Bandura's proposition (Kaplan et al., 1984, Kohler et al., 2002). In short, the stronger the perceived personal efficacy and positive outcome expectations, the more active engagement and persisting effort will apply.

Whether one's expectation of self-efficacy is optimistic or pessimistic, it is based on four principal sources of information: 1) performance accomplishments; 2) vicarious experience; 3) verbal persuasion; 4) physiological states (Bandura, 1977, Bandura, 1986). Performance accomplishments are the most influential source of information because it originates from authentic mastery experiences, whereby successes boost efficacy expectations and repeated failures weaken them, especially early in the course of events. The literature supports the view that performance mastery establishes and enhances self-percepts of efficacy with regards to health (Bourbeau et al., 2004, Kaplan et al., 1984, Oleary, 1985). And providing experiences of performance mastery is an effective strategy to establish and strengthen self-efficacy and enhance efficacious expectations for success in managing similar health threatening conditions in the future. To sum up, the effectiveness of building up one's self-efficacy depends on the mode of delivering information. Also, to enhance patients' perceived self-efficacy in self-management of illness, the key step is to cognitively instil beneficial outcomes of self-management and provide learned experiences to promote positive efficacy expectations of self-managing. Then, this may assure the likelihood of COPD patients' participation and persistence in self-management.

4.4 Interrelationship of Illness perception and Self-efficacy with Behavioural Change

Instead of treating illness perception and self-efficacy beliefs as two separate schools, there is a potential to integrate them when pursuing self-management behaviours. Firstly, both theories provide health care professionals with a basis from which to understand the behaviour formulation of patients and how patients interpret the events or experiences that affect them and construct responses from cognitive processing. Similarly, illness perception involves the cognitive processing of illness belief and self-efficacy involves the cognitive processing of efficacy belief. Using one or other of these two approaches may capture patients' beliefs at the expense of overlooking their expectations of ability or *vice versa.* Secondly, adopting self-managed may appear to be a threatening event to the traditional dependent role of COPD patients, that possibly hinders the illness belief and efficacy belief of the patients. Both beliefs therefore play an important role in guiding the coping response and efforts in self-management. Behavioural response and subsequent appraisal are driven by the perceptions of illness in the patients, whose behaviour represents a 'common sense' response to their cognitive and emotional interpretation of symptoms and health information in the process of belief formulation. This belief of illness, in turn, guides the appraisal of the personal efficacy (Horne and Weinman, 2002). Hence, self-perception and self-efficacy are unlikely to be separate strands in inducing self-managing behaviours in the patients, while they interrelate and supplement closely with each other in bridging knowledge and action (Refer to figure 2).

In reviewing the literature, each approach is found inadequately explaining the cause of a particular health-related behaviour or response. Leventhal et al. (2008) suggested that both motivation elements (attitudes, intentions) and action elements (action plan and personal efficacy) are essential for healthy or risk-reducing behaviours. Having only one or the other may be insufficient to generate behaviour. For example, To enable the COPD patients in Macau to adopt the self-treatment guidelines (action plan) which requires them to identify the signs and symptoms of an exacerbation and

then take different medications, it may be inadequate to build confidence in them in managing the treatment plan by merely equipping them with a motivation element (favourable illness perceptions). Moreover, one's illness representation can affect one's perceived effectiveness of behavioral strategies and perceived competence to manage their illness, especially in cases of chronic illness. Representation of specific self-vulnerabilities or depressing moods that hinders patient's participation in health-relevant behaviours are considered to be affected by personal traits, but how it relates to and mediates these specific behaviours or biological vulnerabilities remains unclear (Leventhal et al., 2008). However, a self-efficacy approach tries to fill the theoretical gap by explaining that perceiving physical infirmities and an inability to attain previously achievable valued performances can be highly depressing. Depressive modality can be more influential than physical incompetency in impairing personal efficacy to initiate and persist with adaptive activities. Perceived self-efficacy and depressive mood, in this case, affect each other bidirectionlly (Bandura, 1989). The impact of induced mood may well lead one to deduce the correlation between the representation of depressing mood and shrinking behaviours.

Although there are not many studies relating both beliefs, it is clear in a series of publications of Lau-Walker both that there is significant relationship between illness perceptions and self-efficacy, and that illness perception components predict self-efficacy. She found that the greater one perceives the consequences of the condition resulting (consequence component of illness perception), the lower general self-efficacy appears to be available to cope with the condition (Lau-Walker, 2006, Lau-Walker, 2004). The resulting belief will intervenes over time forming a long-time lifestyle if no intervention interferes at the early stage (Lau-Walker, 2007). Both theoretical and empirical claims enlist the need to integrate both stances of illness representation and personal efficacy in assessments aimed to gain a more comprehensive understanding of patients' reactions to their conditions and treatment. Furthermore, Johnson (1999) illustrated that a combination of self-regulatory intervention (instruction in coping) and self-efficacy promoting intervention (self-care activities) is more effective than adopting either approach singly for reducing negative response and enhancing general coping in patients (Johnson, 1999).

This suggests that there is more to the responding behaviour than increasing confidence of self-efficacy or *vice versa*. Therefore, both theories supplement each other to induce health-related behaviours. On the other hand, illness perception serves as a threshold of self-efficacy and both approaches eventually influence self-management behaviours. Accordingly, cognitive information and self-management skills aiming at enhancing both the illness representation and personal efficacy should be incorporated in the design of self-management education research for COPD patients.

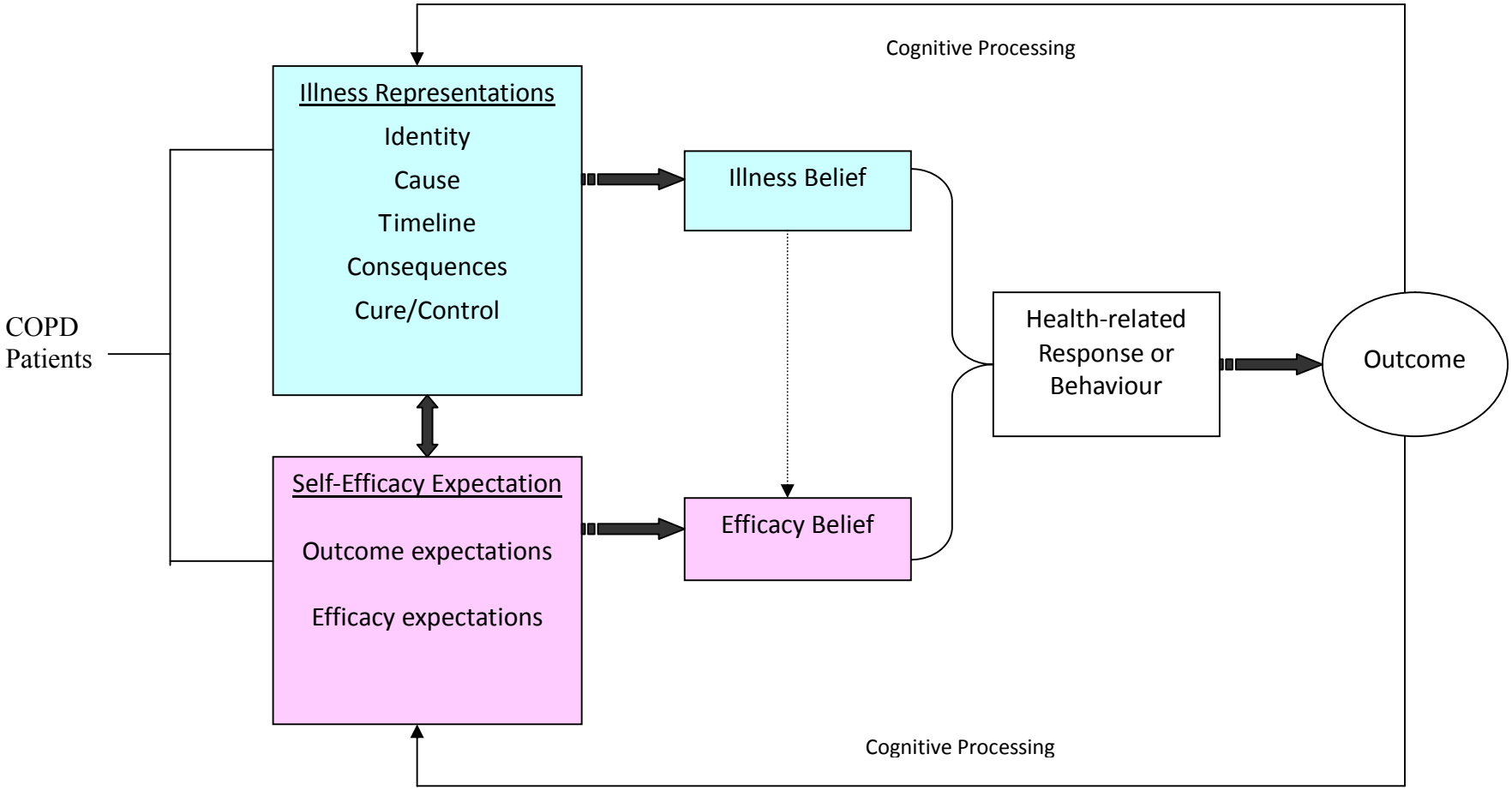


Figure 2. Interrelationship between illness perception and self-efficacy in health-related behaviour of COPD patients.

4.5 Summary

Two cognitive-behavioral theories, namely illness perception and self-efficacy beliefs are employed as the main structure of the theoretical framework of this study. These two beliefs have demonstrated an association in mediating a change in health behaviour in cardiac patients and that may then enhance the potential for the improvement of ultimate goal, for instance, pulmonary function, HRQoL and healthcare utilization in COPD patients. However, the impact of these two beliefs has not been examined in COPD patients with an integration of SMEP. Under these circumstances, the following chapter will identify the research hypothesis and aims and will then expound the overall design of the study with particularly consideration of the discussion in the literature review.

Chapter Five Study Design

5.0 Introduction

Since there has been a lack of experiences and studies of the effectiveness of self-management intervention to COPD patients in Macau, as an initiative study, my research questions included two aspects: (1) the effects of self-management interventions developed in the West on COPD patients in Macau, (2) the subjective perception of the patients on this newly approach. These research questions led to the study design of using a mixed methods approach which was embedded within an experimental design.

In this chapter, focus is given on the philosophical assumptions of this study design and sampling issues. These are related to four main concepts: embedded design, experimental design, complex intervention and mixed methods. The whole chapter is divided into five sections. Section one: The research hypothesis and research aims will be addressed followed by the rationale for accommodating an embedded design in a traditional experimental design and the methodology in relation to how and what methods were mixed. Section two: The rationale and implementation of sampling strategies adopted will be presented together with the methods used for data collection for the quantitative strand. Section three: The qualitative approach used for sampling and data collection in the mixed method design will be given. Section four: The development of the intervention of this study, SMEP, will be addressed with respect to MRC's (2008) framework for complex intervention development. Section five: The data analysis strategies for both quantitative and qualitative strands will be presented and a special focus will be given to the approach of connecting quantitative and qualitative data. These five sections form the fundamental basis for the rigor process and findings of the study.

5.1 Section One Research Aims and Methodology

5.1.1 Research Hypothesis

5.1.1.1 Null Hypothesis

Self-management education does not have positive effects on the biomedical condition, health-related behaviour, psychosocial belief and overall well-being in COPD patients in Macau.

5.1.1.2 Alternative Hypothesis

Self-management education has positive effects on the biomedical condition, health-related behaviour, psychosocial belief and overall well-being in COPD patients in Macau.

5.1.2 Research Aims

- To compare the illness perception, self-efficacy, inhaler technique, pulmonary function, healthcare utilization and health-related quality of life of Macau COPD patients before and after implementation of self-management education.
- To compare the illness perception, self-efficacy, inhaler technique, pulmonary function, healthcare utilization and health-related quality of life of Macau COPD patients who have undergone self-management interventions and who have received conventional therapy.
- To explore the mediating effect of illness perception on self-efficacy of COPD patients
- To identify the factors which positively affect Macau COPD patients' illness perception, self-efficacy and health-related quality of life.
- To explore the perception and experiences of Macau COPD patients towards self-management.

5.1.3 Rationale for the Study Design

5.1.3.1 Philosophical Assumption

The study was based on an embedded design where a mixed methods approach was employed within a traditional experimental design. Embedded design was initially named 'dominant-less dominant study design' and previously 'nested design', these similarly referred to the methods and results relating to the dominant paradigm with a small component of a less-dominant paradigm residing in it (Creswell, 1994). This design enables the collection and analysis of different types of data in order to enhance the application of an experimental design to address the primary propose, namely the effects of self-management education on COPD patients, of the study (Creswell and Plano Clark, 2011). As a qualitative strand was planned within the main experimental design, there should be an alternative paradigm in additional to post-positivism of which experimental design is typically used. In this way pragmatism was the philosophical basis for this study (Teddlie and Tashakkori, 2009). Firstly, due to my personal perspective of the world, I believe that there is not at all an absolute 'truth' or 'reality' that we can identify or assert, since truth exists on a continuum rather than on either objectivity or subjectivity while reality varies from a single fact to a construct of multiple perspectives and meaning as long as the methods applied can achieve it. Secondly, it is because the proposed research questions are primarily oriented to inform about the use of a mix of quantitative (confirmatory) and qualitative (exploratory) approaches. Pragmatism sees the compatibility of quantitative and qualitative methods and it is open to a mix of methods if the research questions and practicalities of the research context suggest it (Brannen, 2005). Pragmatists criticize any distinction between absolute objectivity and subjectivity and the epistemological issues existing on opposing poles of positivism and constructivism, so it allows any methods to be employed which achieve best explanations of the feasibilities and effectiveness of self-management in COPD patients in the given study. Moreover, a pragmatist always preconceives theoretical accounts of the world with suspicion, I should even be tentative and open

to empirical correction (Jarvie and Zamora Bonilla, 2011). In additional to identifying the epistemological stance employed in mixed methods study, it was also necessary to examine the justifications for using mixed methods in an experimental design wherein the quantitative approach is predominantly the methodology.

5.1.3.2 Mixed methods in Experimental Design

Mixed methods approach involves incorporating multiple methods in a project and needs much reflection on the justification of adopting such a combination (Fielding, 2008). It is important to start with an examination of the definition of mixed methods. After decades of refinement, Creswell and Plano's (2011) most updated definition for mixed methods combines the core characteristics of the approach in relation to methods, a philosophy and a research design orientation.

> *"In mixed method, the researcher :*
>
> - *Collects and analyses persuasively and rigorously both qualitative and quantitative data (based on research questions);*
> - *Mixes (or integrates or links) the two forms of data concurrently by combining them (or merging them), sequentially by having one build on the other, or embedding one within the other;*
> - *Gives priority to one or to both forms of data (in terms of what the research emphasizes);*
> - *Uses those procedures in a single study or in multiple phases of a program of study;*
> - *Frames these procedures within philosophical worldviews and theoretical lenses; and*
> - *Combines the procedures into specific research designs that direct the plan for conducting the study."* (Creswell and Plano Clark, 2011, P. 5)

In this study, a mixed methods approach was chosen based on research questions. As addressed in the previous philosophical inquiry, the given research questions of this study bear both confirmatory and explanatory statements where mixed methods are compatible. In addition, this study aims to evaluate the effects of a self-management education programme on COPD patients. SMEP comprises multiple components and is usually regarded as complex intervention (Details see Chapter three, section 3.4).

Mixed methods embedded in an experimental design may be particularly useful for research studies evaluating complex interventions as such on human beings. Unlike pure laboratory experiment, complex interventions involve more than one independent variable, and outcomes may be interweaving and due to many different reasons. In spite of merely pursuing the objective truth through quantitative methods, the qualitative data collection method used in an experimental design can additionally better understand qualitative differences between groups, including differences in the reactions of subjects to the experimental conditions and experiences underlying experimental effects (Polit and Hungler, 1997). In other words, qualitative data illuminates the meaning of statistical results by adding a narrative understanding to the numeric findings (Hesse-Biber, 2010). However, there were claims for the potential technical flaws in regard to methodological interaction and prioritization (Fielding, 2008). Special attention is needed to recognize this "add-ons" component being in no way as important as the hypothetico-deductive-driven approach in an experimental design (Tashakkori and Teddlie, 1998). Creswell and colleagues (2008) also acknowledged the qualitative approach as supplemental rather than subordinate or unobtrusive simply due to its intrinsic nature (Creswell et al., 2008). Thus, the supplemental qualitative approach may help explain or augment findings generated from the larger quantitative approach and probably enhance the overall experimental design in some way (Bryman, 2008, Bryman, 2006).

In other words, the combination of quantitative and qualitative methods helps to enhance and clarify the findings from one method with the findings from another, providing different aspects and depth of examination on the effects of a complex intervention. More importantly, the complexities of social beings are not just treated as some figures, but studied directly in order to project the subjective views of the world and obscuring insights (Watson, 2008, Polit and Beck, 2010, Keady and Watson, 2008). This mixed methods approach in experimental design may lead to knowing whether and how the complex interventions are effective and/or ineffective for the participants, which eventually helps to streamline the self-management programme and make it more efficient and cost-effective.

5.1.4 Methodology

5.1.4.1 Exploratory randomized controlled trial

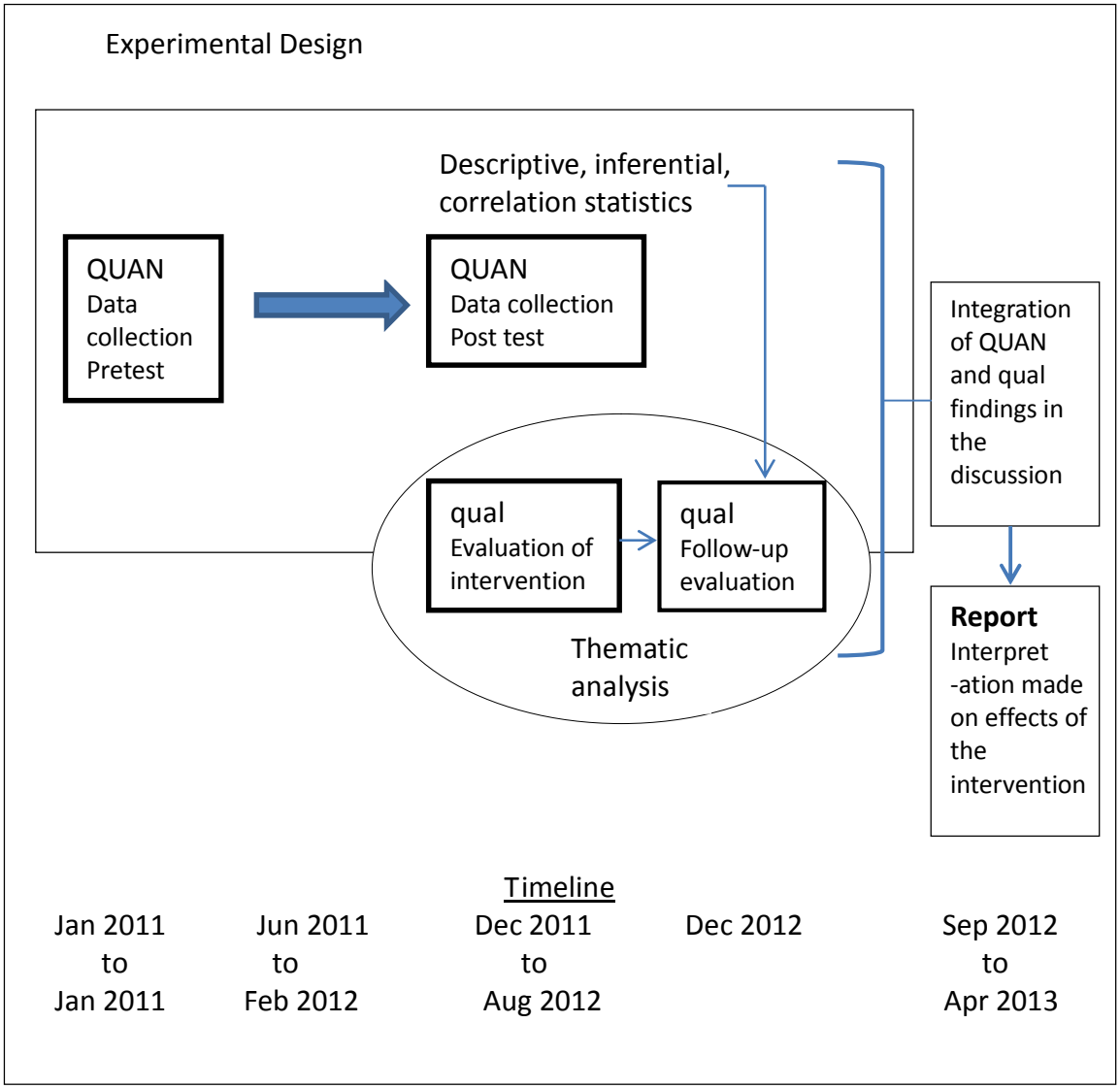
A randomized controlled trial (RCT) comprised a random allocation of participants, a control and an intervention for testing (Polit and Beck, 2010, Smith, 2008). Here, eligible participants were randomly allocated to either an experimental group (self-management group, SMG) which received an intervention (SMEP) in addition to conventional therapy or a control group (CG) which just received conventional therapy. Pre-test and post-test assessments were conducted to examine changes in dependent variables (for instances, biomedical, psychosocial, behavioural and subjective aspects) after the intervention when the two groups were compared (Polit and Beck, 2010). To date, no RCT studies have ever explored the effectiveness of the implementation of any nursing care / rehabilitative programme for COPD patients or self-management intervention for patients with any chronic disease in Macau. It is anticipated an exploratory trial will identify potential relationships between varying components and will provide a basis for a definitive RCT in the region. Exploratory trial is the second phase of evaluation of RCT for complex interventions to improve health and is the crucial stage prior to a main RCT (MRC, 2000, MRC, 2008). All evidence gathered in this phase can inform the intervention and be tested on varying components to see what effect each has on the intervention as a whole.

5.1.4.2 Mixed methods

In this design, I used two methods to address different research questions and collected data in three phases: the first phase is for pre-test, second phase is for post-test (six months after intervention) and third phase is the follow-up of second phase (as shown in diagram 1). A shorthand notation was used to describe the design: QUAN(+qual). This notation indicates:

"*an embedded design in which the research implemented a secondary qualitative strand within a larger quantitative experiment, the qualitative methods occurred during the conduct of the experiment, and the qualitative strand enhanced the conduct and understanding of the experiment.*" (Creswell and Plano Clark, 2011, P. 110)

Diagram 1 Relationship of different concepts in the Embedded design, QUAN(+qual)



In the quantitative strand, validated questionnaires and scales were used to collect quantitative data regarding illness perceptions, self-efficacy, and health-related quality of life respectively. In the qualitative strand, focus groups were conducted on patients from the experimental group to explore their experiences and perceptions of self-management. However, it is necessary to consider how methods can complement

each other, their relationship and their sequence, rather than simply throwing together different methods (Barbour, 2008).

Regarding the approach of mixing, a concurrent as well as a sequential approach for data collection were employed (Creswell and Plano Clark, 2011). Throughout the process, quantitative data was the primary focus and was initially collected in the first phase to establish a baseline assessment of the subjects. In the second phase, both quantitative and qualitative data were concurrently collected to specifically answer differing aspects of research questions. Quantitative data was collected to evaluate the outcomes of the intervention in terms of statistic description and inferences, while the secondary qualitative data was to examine potential meaning of self-management to COPD patients in Macau. Then, both sets of data were analyzed independently. In the third phase, sequential data collection and analysis took place. It was a subsequent collection and analysis of qualitative data that was informed by the data collected in the post-test phase. The third, sequential qualitative phase built on the second concurrent phase, and data of the two phases were connected and compared in the discussion section wherein the conclusion of the study was developed. The data collected in the third phase helped to enhance understanding of how subjects viewed the results of the trial (Creswell and Plano Clark, 2011). In this way, the rationale for this approach was that the quantitative strand of the study aimed at identifying factors that statistically associated with participants' overall well-being before and after interventions, whereas the qualitative strand focused on explaining the processes whereby this occurred (Bryman, 2006).

5.1.5 Section Summary

The testing of self-management intervention, an initiative nursing approach, has led to the development of two research questions of this study which were of confirmatory and explanatory nature. An embedded design was thus adopted where a primary focused quantitative approach combining with a supplemental qualitative approach within a traditional experimental design was used to answer these two questions. Pragmatism was discerned to be the philosophical foundation of the study

as it accommodates different methods and different forms of data rather than adopts an either-or stance. Based on this paradigm, I have tried to depict the multiple scopes of mixed methods used in exploratory RCT for examining effects of complex intervention, namely the SMEP in this study. Also, through stating the rationale of using this approach, namely timing, sequence and strategy of mixing the data, the findings of this study were anticipated to have demonstrated rigor inferential conclusions as well as to have incorporated the insight into perceptions by patients of their own situation. The next step of the study design is the sampling and data collection issues. Hence, in the next two sections, both issues will be presented with regard to the quantitative and qualitative approaches respectively.

5.2 Section Two Sampling and Data Collection Strategy for the Quantitative Strand

5.2.1 Study Population and Sample

In the quantitative strand, the target population of the research is COPD patients in Macau. Sampling was planned to be conducted at one of the two largest hospitals, two largest health centers of the Health Bureau and the elderly day care centers of Macau. Patients who fulfill the GOLD's (2008) diagnostic criteria of COPD Stage II & IV were selected from medical wards, respiratory out-patient departments of the hospital, the health centers and the elderly day care centers suggested.

5.2.1.1 Inclusive criteria for sample selection

- Post-bronchodilator FEV_1 of stage II, III and IV COPD stated by GOLD in 2008, measured by the same validated spirometry.
- COPD refers to emphysema, chronic bronchitis and the chronic asthmatic condition that their airflow limitation is not fully reversible.
- COPD patients with concomitant diseases and conditions are included as long as the patients are not in the acute stage of those diseases/conditions at the time of recruitment.
- Participants should be 40 years old or above.
- Participants in Macau should understand Cantonese and communicate in written Chinese.
- Participants' consent is freely given to take part in the research upon fully informed about the process and risk of participation and autonomous decision.
- Participants are in a stable stage of their disease and approved by their attending doctor as competent for participating in the study.

5.2.1.2 Exclusive criteria for sample selection

- Stage I COPD patients according to the GOLD's (2008) spirometric classification of COPD.
- Patients with reversible asthma, congestive heart failure, lung carcinoma, bronchiectasis, pulmonary tuberculosis, bronchiolitis obliterans and interstitial lung diseases who may present reversible airflow limitation during respiration.
- COPD patients who are in the acute condition of concomitant diseases or who come for treating their concomitant diseases.
- Patients who are in acute stage of an exacerbation of COPD, cognition impaired, deficit in mobility or unwilling to participate in the research.

5.2.2 Sampling Procedures

5.2.2.1 Research ethical review and Participant recruitment

This study was approved by the subject area research ethics team/coordinator of the School of Health in Social Science of the University of Edinburgh (See Appendix 2). Formal applications for research sampling were sent to the suggested hospital, the Health Bureau and eight elderly day care centers in Macau. The application to the suggested hospital was approved [No.(11)001] (See Appendix 3), while the Health Bureau and one elderly day care centre rejected the application. The reasons of rejection were keeping confidentiality for their patients and unavailability. Potential eligible participants were selected from medical wards and respiratory out-patient departments of the hospital. The recruitment of participants happened at the end of the out-patient visit or about discharge from hospital admission, through either referring or approval from the physicians of the respiratory team of the hospital as well as referral from the person-in-charge of the elderly day care centres. All patients approached were obtained verbal consent before assessing and confirming their eligibility for participating in this trial.

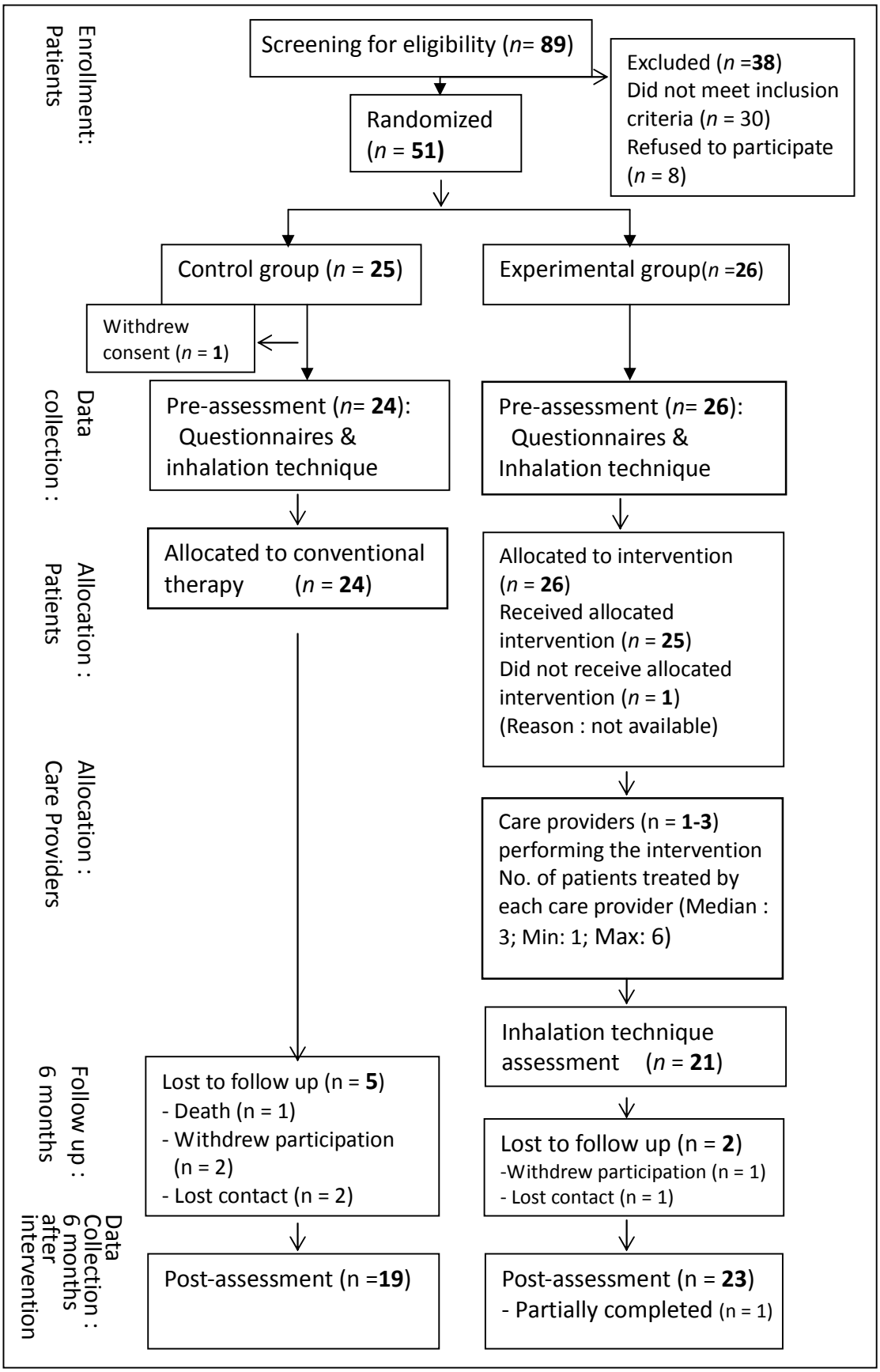


Figure 3 Trial profile

5.2.2.2 Sample Size

As a phase II exploratory trial, sample size calculated by power analysis for achieving minimal clinical significance was unlikely required (MRC 2008). The sample size was then planned to reach a minimum of 50 to enable basic statistical analysis for informing potential relationship of various concepts in the modelling stage. In practice, 89 patients were approached (Refer to Figure 3). They were informed about the aims and process of the study and their rights in the due course, followed with spirometric tests for verifying the eligibility of the patients. 51 patients fulfilled the inclusive criteria.

The main reasons for exclusion were because the patients (42.7%, 38 out of 89) did not fulfill the inclusion criteria by having a history or condition of bronchiectasis, pulmonary tuberculosis, congestive heart failure or classifying into stage 0 according to the GOLD's (2008) spirometric classification of COPD. Eight patients (9.0%) refused to participate in the study, of which most of them regarded useless to attending the SMEP and one previously had received pulmonary rehabilitative training in Hong Kong. Three patients were unable to complete the assessment and were therefore excluded.

5.2.2.3 Randomization

All 51 eligible subjects were randomly allocated to either SMG or CG. SMG underwent the SMEP in additional to conventional treatment and CG received only conventional treatment. Subject allocation was based on block randomization (MRC, 2000), in which each subject was assigned to a block in accord with his/her stage of COPD and he/she randomly picked a card stating either SMG or CG. To balance the number of subjects of each stage of disease in each group, there were an equal number of cards of both groups in each block (stage of disease). I performed randomized consent by obtaining the written informed consent in terms of the assigned group of the subjects (Information sheet and consent form see appendix 4, 5,

6, 7). This approach may be ethically preferable to a conventional design where it would be intolerable for those in the CG to know that a potentially beneficial intervention was being denied through randomization (MRC, 2008). Then, the consented subjects were scheduled baseline assessments (Tier 0 assessment or T0). However, one subject from the control group withdrew consent with a reason of being unavailable for the trial before the baseline assessment took place. Therefore, a total of 50 subjects (26 subjects in SMG and 24 subjects in CG) participated in the trial (Figure 3).

5.2.2.4 Blinding and Bias minimization

In group allocation, single-blind technique was applied to the subjects, so they were unaware of which group they were in (Smith, 2008). Moreover, persons who delivered the intervention were not responsible for conducting the post-intervention assessment. Also, the investigators who performed post-intervention assessment were blinded to group assignments so as to minimize bias on outcome data (Smith, 2008).

5.2.2.5 Dropout of participation

During the study, one subject in SMG did not complete the SMEP as she was repeatedly absent from the scheduled educational workshops. All subjects in the SMG received an assessment of their inhalation technique of the inhalers at the completion of the self-management workshop (Tier one assessment or T1). During the six-month follow-up, one subject in SMG and two subjects in CG withdrew participation from the T2 assessment. Two subjects from SMG and two subjects from CG were unable to be contacted, and one subject from CG had died. At the end of the study, the number of subjects who completed T2 assessment was 23 for SMG and 19 subjects for CG. The dropout rate was 17.6%.

5.2.3 Method of Data Collection

Both quantitative and qualitative data were collected to assess effects of

self-management interventions on Macau COPD patients in this embedded mixed methods design. This section only describes the method of quantitative data collection while the qualitative part will be presented in the next section. All aspects of outcome assessment are displayed in figure 4 in relation to the theoretical framework. In the quantitative strand, assessment of the demographic, biomedical, psychosocial and behavioral aspects of the subjects was done through questionnaire investigation and pulmonary function testing and behavioural checking. (Questionnaire sample see appendix 8; demographic data see Appendix 8 section 1). It is unwise to put focus on all measurements, so I posited primary outcomes and secondary outcomes of the trial based on the proposed theoretical framework and literature review. In the following, I will address all measures selected and utilized for assessing both the primary outcomes (Illness perception, self-efficacy, inhaler technique) and the secondary outcomes (pulmonary function, rescue medication and healthcare utilization, health-related quality of life) of this study in terms of their characteristics, measurement properties and clinical application.

5.2.3.1 Primary Outcomes

Provided that COPD is incurable, but treatable and preventable in nature, lost pulmonary function would largely be unable to restore by existing medical and nursing interventions (GOLD, 2013, ATS, 2004). Reducing mortality and improving pulmonary function were certainly not the aims of the study whereas the psychosocial and behavioral outcomes were taken into consideration. In the light of the theoretical framework and literature review, the intent of SMEP clearly was to enhance the illness perception and self-efficacy and subsequently the health behaviour of COPD patients. Illness perception and self-efficacy belong to the psychosocial dimension while and health behaviour belongs to the behavioral dimension of an individual. Therefore, the primary outcomes were illness perception, self-efficacy and inhaler usage technique and relevant measures adopted should reflect the dimensions in question and also the research purpose of interest. I will first present the Revised Illness Perception Questionnaire (IPQ-R) and COPD Self-Efficacy Scale (CSES), followed by the assessment inhaler technique.

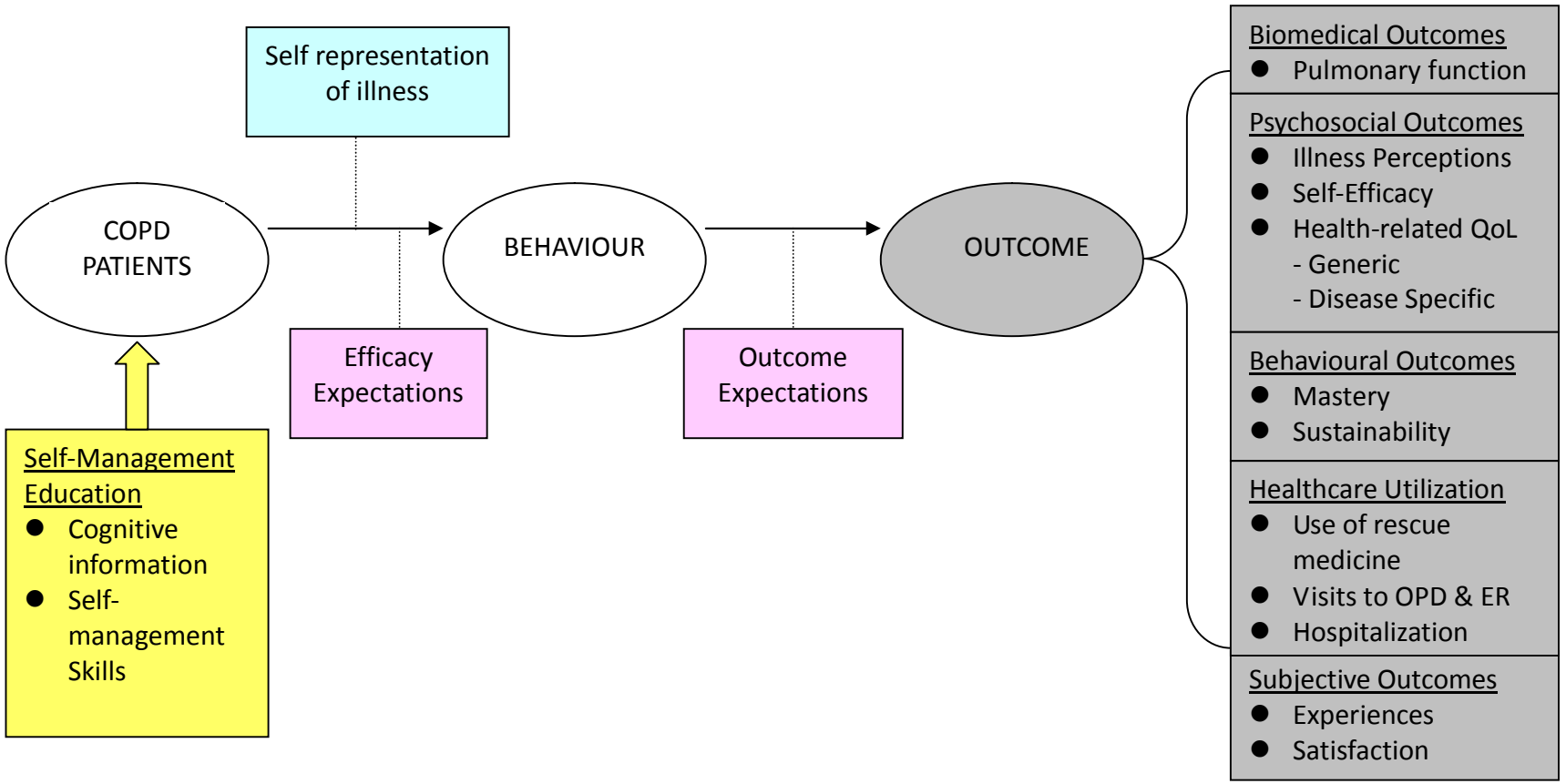


Figure 4. Theoretical framework of observing the effects of self-management education programme on COPD patients.

5.2.3.1.1 Psychosocial data collection

Measurement scales such as The Revised Illness Perception Questionnaire (IPQ-R), COPD Self-Efficacy Scale (CSES), Medical outcomes study 36-item short form health survey (SF-36) and St. George Respiratory Questionnaire (SGRQ) are used to assess the psychosocial aspects of the participants before and 6 months after the self-management intervention. Since Macau population share the same written and spoken language of Hong Kongers, traditional or Hong Kong Chinese version of these four questionnaires are used (Chen et al., 2008b, Lam et al., 1998, Yu et al., 2004). Application for purchasing the license of using SF-36 is approved by the QualityMetric Incorporated, and other three scales are granted permission by the authors to be used for free in this study.

5.2.3.1.1a Illness Perception Measurement

The revised version of illness perception questionnaire (IPQ-R) was used in this study (Appendix 9). This questionnaire is divided into three sections: Identity dimension, illness representation dimension and causal dimension. Identity dimension is presented in the first section including 14 commonly experienced symptoms and each symptom is rated on a yes or no response format. The sum of the yes-rated items on this rating forms the illness identity subscale. In the illness representation dimension, seven subscales such as consequences, timeline acute/chronic, time cyclical, personal control, treatment control, illness coherence and emotional representatives are presented in 38 items rating on a five-point Likert-type scale: strongly disagree, disagree, neither agree nor disagree, agree, and strongly agree. Mean scores of each item for every subscale were calculated for both the identity and illness representation dimensions. The causal dimension is divided into two sessions. In the first session, the subjects are required to self-report three causal items attributional to their COPD. A percentage on the accumulation of the three attributions reported by all patients was presented. In the second section, the participants rate on 18 given attributional items in regard to the cause of their disease with the same Likert-type scale.

The 18 attributional items are categorized into four main attributional factors: Psychological attributions, risk factors, immune system factors and chance factors. However, it is inappropriate to sum all of the items as each item represents a specific causal belief (Weinman et al., 1996). Thus, I provide the sum of each of the four attributional factors and an average rating of each item. Regarding the measurement properties of IPQ-R, the three sections show an acceptable consistency in assessments and good structural validity and all the subscales demonstrate good internal reliability with Cronbach alpha's of 0.75 in the first section, 0.79 to 0.89 in the second section and 0.67 to 0.86 in the third section (Moss-Morris et al., 2002). The revised illness perception questionnaire (IPQ-R) was translated into traditional Chinese version (See appendix 8: Section 5) and is available on the web (http://www.uib.no/ipq/pdf/IPQ-R-Chinese.pdf). However, its psychometric properties have not been shown.

5.2.3.1.1b Self-Efficacy Measurement

The COPD Self-Efficacy Scale (CSES) was chosen and it consists of 34 items which explore five dimensions, (for instances, negative effect, intense emotional arousal, physical exertion, weather/environment and behavioural risk factors) of COPD patients (Appendix 10). The five factors show a good validity and its reported internal consistency was satisfactory, having the Pearson product-moment of test-retest reliability correlation coefficient of 0.77 ($p<0.001$) (Wigal et al., 1991). It was claimed that the CSES would be useful in measuring increases in self-efficacy following an educational or self-management intervention. Nonetheless, caution is needed in interpreting results based on individual scores since it was established on a group basis (Wigal et al., 1991). In Wong et. al.(2005)'s study, CSES was translated into simplified Chinese by an English to simplified Chinese and back translation method (Wong et al., 2005). It achieved a content validity index ranging from 0.64 to 0.85 and three items were removed from the original English version, resulting 31 items covering five subscales: negative effect (11 items), intense emotional arousal (seven items), physical exertion (six items), weather or environment (five items),

behavioural risk factors (two items). The final simplied Chinese CSES version demonstrates good test-retest reliability of correlation coefficient r=0.88. I have contacted Wong and was granted permission to use the scale. However, this simplified Chinese CSES has neither validated on a large population nor external validity confirmed. As simplified Chinese is usually expressed in Mandarin orally, this version is not totally applicable in Macau because Macanese basically reads traditional Chinese and speaks Cantonese. In this case, I have converted the simplified Chinese version into traditional Chinese version. Three experts in nursing, education or clinical respiratory nursing who comprehend both forms of Chinese were invited to validate the items of the scale with respect to language expression. The content validity index (CVI) was computed and it reached 0.91 (ranged from 0.67 to 1.00). Refinement in the wordings was performed on four items of the scale as recommended by the experts. The final version of traditional Chinese CSES was administered to three COPD patients for assuring understanding before data collection, no major revision was recommended (See appendix 8: Section 4).

5.2.3.1.1c Inhaler technique

When we assess the self-efficacy of an individual on a specific task or action, it was advised to assess his or her performances as well (Jiang et al., 2004). To assess COPD patient's self-management behaviour, researchers often examined the mastery rate of inhalation skills or inhalation technique of them (Bourbeau et al., 2004, Rootmensen et al., 2008). In this study, however, I assessed inhaler technique of the subjects. In inhaler technique assessment, both the inhalation technique and proper inhaler care were included. A device-specific inhalation checklist which lists the proper steps of each type of inhaler was developed according to the instructions given by the relevant pharmaceutical companies. The mastery rate of the usage of all prescribed inhalers was assessed through the observation of the inhaler technique of the participants (Appendix 11). The mastery rate of inhaler technique was presented in a percentage which was computed through dividing the sum of correct steps by the total steps of the inhaler technique. Total scores range from 0% to 100%, with higher scores indicating better performance.

5.2.3.2. Secondary Outcomes

5.2.3.2.1 Biomedical measurement

Pulmonary function parameters such as post-BD $FEV_{1,}$ post-BD FEV_1% predicted were examined to assess the condition of the airway after administrating bronchodilator. Pulmonary function is usually assessed by spirometry, and both post-BD FEV_1 and post-BD FEV_1/FVC serve as the clinical criteria for diagnosing and monitoring COPD. To obtain these measurements, I followed the pulmonary function test instruction advised by GOLD (2008). The subjects were instructed to blow at a spirometric device (Model: Spirobank II). Four to five blows were generally needed to optimize the readings of both FEV_1 and FEV_1/FVC. In regard to assessing post-BD FEV_1 and post-BD FEV_1/FVC, standard dose of short-acting β_2 agonist (bronchodilator 400 μg) was administrated to the patient either through a nebulizer or spacer and spirometry was repeated 10~15 minutes later. The presence of a post-BD FEV_1< 80% of predicted and post-BD FEV_1/FVC < 0.70 confirms the presence of airflow limitation which is a typical finding in COPD patient. After obtaining the measurements before and after bronchodilator administration, the difference was then calculated and divided by the pre-test value and expressing it as a percentage. If there is an increase of <12% and 200ml, it indicates a lack of bronchodilator reversibility (GOLD, 2008). The above test was carried out on condition that the patient had not inhaled short-acting bronchodilators in the previous six hours, long-acting bronchodilators in the previous 12 hours, or intaken sustained-release theophylline in the previous 24 hours.

5.2.3.2.2 Rescue medication and Healthcare utilization

A COPD patient may presumably be in stable condition when he is on regular treatment. But if he experiences exacerbation or severe symptoms and regular treatment could not relieve the condition, he may need to use rescue medication, for instance, short-acting bronchodilator (SABA), prescribed oral corticosteroid, and

antibiotics (GOLD 2013). If rescue medication as such could not relieve the condition, he may need medical consultation at out-patient department or emergency room depending on the perceived severity with the patients. Thus, the consumption of rescue medication and demand of healthcare service could reflect the stability of the disease of the patients. In this study, the frequency of using SABA, number of unplanned out-patient or emergency room visit and number of days of hospitalization of the participants were assessed. For the frequency of using SABA, the subjects were asked to base on their own practice in six months reporting among choices including: Never use, two times/week, two to seven times/week, once per day and more than once per day. For healthcare utilization, number of self-reported unplanned out-patient or emergency room visit usually refers to the unscheduled doctor and nurse visits per patient in a specific period of time (Effing et al., 2007, Bourbeau and van der Palen, 2009) (See general section of appendix 8). I took this as the definition for assessing this variable by taking into account that unscheduled visit was due to respiratory condition and happened in the past six months. Moreover, hospital admission and hospital days were defined by counting times of hospitalization and total days of hospitalization due to COPD exacerbation respectively in a specific period of time (Effing et al., 2007). The participants in this study were requested to report the total number of days of hospitalization in relation to COPD exacerbation in the past six months.

5.2.3.2.3 Health-related Quality of Life measurements

Generic HRQoL measure (SF-36v2) and disease-specific HRQoL measure (SGRQ-HK) were used to assess the quality of life status of the participants. Since Macau population share the same written and spoken language of Hong Kong residents, as such traditional or Hong Kong Chinese version of the two instruments are applicable in Macau (Chen et al., 2008b, Lam et al., 1998, Yu et al., 2004). License of using SF-36v2 has been purchased from the QualityMetric Incorporated which developed the instrument (See appendix 12). For SGRQ-HK, permission was granted by the authors for using it for free in this study.

5.2.3.2.3a Generic health-related Quality of Life

For the assessment of generic HRQoL, the Chinese (HK) version of the SF-36 (SF-36v2) was used in this study (See Appendix 8: Section 2). It was first validated against the original U.S.-English SF-36 by Lam and her colleagues in 1998 and the two questionnaires were found to be equivalent in concepts and measurements (Lam et al., 1998, Lam et al., 2005). The SF-36v2 is a self-administered generic HRQoL instrument for the assessment of a general health status in a month period. It has 36 items covering eight domains including physical function, role-physical, bodily pain, general health, vitality, social function, role-emotional and mental health (Ware, 2005). Physical functioning (PF) consists of 10 items and reflects levels and kinds of limitations between the extremes of physical activities ranging from strenuous sport to dressing oneself. Role-physical (RP) consists of four items which cover an array of physical health-related role limitations. Bodily pain (BP) comprises two items which pertain to the intensity of the bodily pain and the extent of its interference with normal work activities respectively. General health (GH) comprises five items which include a rating of overall health and four items addressing the subject's view and expectations of his or her health. Vitality (VT) has four items which capture differences in one's subjective well-being, for instance, energy level and fatigue. Social functioning (SF) has two items which assess health-related effects on quantity and quality of social activities. Role-emotional (RE) consists of three items and they reveal mental health-related role limitations. Mental health (MH) has five items which assess major health dimensions with respect to anxiety, depression, loss of behavioral/emotional control and psychological well-being. The eight domains indeed reflect two broad components of health: Physical component summary (PCS) and mental component summary (MCS). PF, RP and BP contribute most to the scoring of PCS while MH, RE and SF contribute most to the scoring of MCS. Two domains (VT and GH), however, contribute substantially to both components. There is no total scoring for SF-36v2, but measures are reflected on the domain scores. The domain scores are calculated through a scoring software (QualityMetric Health Outcomes™ Scoring Software 4.0) provided by QualityMetric Incorporated. In principle, the higher the score of each of the eight domains, the PCS and MCS, the

better the generic HRQoL is indicated (Maruish and Turner-Bowker, 2009).

SF-36v2 bears the scaling success rate on discriminant validity at 92.5% to 100% for all scales. In regard to its internal consistency, the Cronbach's alpha coefficients of internal reliability (RTT) were above the standard of 0.65 for all scales. It is suggesting that the SF-36v2 would be able to detect any deterioration in the health status of these subjects (Lam et al., 1998). However, changes in SF-36 for assessing health status may be underestimated in subjects who show higher baseline scores in the scales of the SF-36. As recommended, disease-specific instrument was used as a complementary approach to assess the HRQoL (Sato et al., 2004).

5.2.3.2.3b Disease-specific health-related Quality of Life

The Hong Kong Chinese version of SGRQ (SGRQ-HK), which is a disease-specific assessment tool for COPD patients, was selected to assess the disease-specific HRQoL status of the subjects before and 6 months after the intervention in this study (See appendix 8: Section 3). SGRQ-HK was translated from original English version of SGRQ and validated by Yu *et al.* in 2004. SGRQ-HK contains of 75 items which are divided into three sections: Symptoms, activity and impacts. The symptoms section reflects the level of symptomatology in terms of frequency and duration of COPD symptoms. The activity section captures physical activities that cause or are limited by breathlessness. The impacts section covers aspects associated with employment, being in control of health, panic stigmatization, the need for medication and its side effects, and expectation for health and disturbance in daily life. There is a special weighting system for calculating SGRQ of which all the subscales with a positive response were summed. The score was then calculated by dividing the summed weightings by the maximum possible weightings for that section, and it results in a total score and three subgroup scores. Thus, a high score indicated poor quality of life (Yu et al., 2004). In Yu et al.(2004)'s study, SGRQ-HK shows validity with a construct of explaining 88% of variance and a high internal consistency with the Cronbach's α of 0.74 averagely across all subscales and total scores. It is stable for repeated measurements over time as its short and long-term test-retest reliability

ranging from 0.97 to 0.98 and 0.70 to 0.86 respectively. It is claimed to be a reliable and valid instrument for assessing QoL in Hong Kong Chinese people with COPD (Yu et al., 2004).

5.2.4 Administration of measures

Before administrating the four chosen measures (IPQ-R, CSES, SGRQ-HK and SF-36v2), I have given to five Macau COPD patients for confirming their understanding to the questionnaires prior to real data collection. The possibility of misunderstanding may be present among the elder adults in Macau who are relatively low educated as 70% of them have received primary education or lower (KWNC, 2004), questionnaires were conducted on a structured interview basis to avoid misinterpretation of the respondents (Bryman, 2008). Six senior undergraduate students of nursing programme were recruited as investigators for this study. To maximize the inter-rating reliability, all investigators were given a four-hour training for learning how to perform pulmonary function testing and for getting familiar and maximizing unity in administrating the assessments. All measures were conducted at T0 and T2 to examine the effects of the intervention. Exceptionally for inhaler usage technique, it was assessed at T0, immediately after the intervention (Tier 1, T1) and T2 to assure the sustainability of the behaviour with the participants after the intervention.

5.2.5 Section Summary

In the final study, two rather than three sectors of proposed sampling venues approved sampling for this study. A total of 50 subjects consented and participated in the experiment of which 26 subjects and 24 subjects were allocated to SMG and CG respectively by block randomization and the study ended up with a total of 42 subjects, indicating 17.6% of drop out. Various measures were used to assess these participants. IPQ-R, CSES and inhaler technique checklist were used to assess the primary outcomes (Illness perception, self-efficacy and inhaler technique), while the post-FEV_1 and post FEV_1%, frequency of rescue medication usage and unplanned

visits to outpatient and ER, days of hospitalization, SF-36 and SGRQ were used to assess the secondary outcomes (pulmonary function, rescue medication usage, healthcare utilization, generic and disease-specific HRQoL) of the experiment. These measures were delineated with respect to their construct, validity and reliability. Moreover, the data collection method and sampling for the qualitative data will be presented in the following section.

5.3 Section Three Qualitative Data Collection and Sampling Strategy

5.3.1 Introduction

Focus groups were conducted on a sub-sample of SMG who received the intervention and completed the quantitative assessment. Focus groups were used to explore at some length concerning issues evolved from the questionnaire results (Fielding and Fielding, 1986). But why focus groups were used rather than one-to-one interview? How could these focus groups be carried out in a way that corresponded to its supplemental secondary role within an embedded design? In this section, I offer rationale for adopting focus groups as method to elicit the views of participants and how this fits with the research aims and present the principles employed in conducting focus groups. As qualitative sampling usually does not aim to produce a representative and 'identical' sample, sampling was focused on approach where the issue central to the research question was explored (Barbour, 2007). So this will also cover the arguments for the determination of the number of focus groups and for purposive sampling in the selection of focus group participants.

5.3.2 Definition of Focus group

The term, focus group has sometimes been used interchangeably with 'group interview', 'focus group discussion' and 'focus group interview' (Barbour, 2007). Focus group was found most frequently used and suitable term for expressing hybrid characteristic. Barbour (2007) also tended to uphold the definition that she drew with Kitzinger in their book published in 1999. Kitzinger and Barbour (1999) defined focus groups as follows:

> *"Focus groups are group discussions exploring a specific set of issues, distinguishing from the broader category of group interviews by the explicit use of group interaction to generate data. Instead of asking questions of each person in turn, focus group researchers encourage participants to talk to one another: asking question, exchanging anecdotes,*

and commenting on each others' experiences and points of view." (Barbour and Kitzinger, 1999, P.4)

5.3.3 Rationale for using Focus groups

Focus group was claimed to be ideal for exploring people's attitudes, experiences, opinions, wishes and concerns and examine people's different perspectives by investigating how points of views are constructed and expressed. Morgan (1998) argued that focus groups may suit to understand complex behaviour and motivation as the interaction among the participants consist of their efforts to understand each other. They are curious to know how people behave and the motivations that underlie these behaviours, so focus groups were regarded as avenue to reveal deep motivational insights (Morgan, 1998). The main feature of focus group making it distinct from one-to-one interview is that researcher can hear new ideas of interest arisen from the group in additional to the prepared topics. Through contact and observation with the participants of this study during implementing SMEP, they were slightly shy and not good at articulating their feelings and opinions. In this case, one-to-one interview may not be an appropriate option to collect data due to its serious atmosphere and higher demand of ability in verbal expression. On the contrary, focus group embraces friendliness and respect in nature and the participants could share more easily (Morgan, 1998). To resolve the issue of shyness in the participants, I intended to provide a familiar setting for this qualitative interview as the participants have already participated in a group intervention and the focus of the interview was on how they as a group made sense out of the intervention. The interpersonal communication in a group may help to clarify similarities and differences in expressed opinions and/or values (Freeman, 2006). Subsequently, by contrasting and comparing among the participants, they could become more explicit about their views.

5.3.4 Conducting Focus Groups

5.3.4.1 Topic Guide and Focus Group Moderator Preparation

A semi-structured interview was employed with the main focus on two elements: perceptions and experiences of the participants towards self-management. An semi-structured interview enabled the participants to throw out their ideas and opinions within their flow of conversation and their interaction, and the two foci can direct the group from running off the topic (Bryman, 2008). Hence, the focus group topic guide was a brief and a focus one (Appendix 13). Since I was the moderator of the self-management education workshops, a fairly good patient-nurse relationship has been built up with the participants. Due to lack of experienced personnel for conducting focus groups, I invited a moderator not involved in the study who had experiences of conducting qualitative interviews to conduct the focus groups. To ensure reliability, training was given to the moderator by introducing the aims and methods of study, the aims of the focus groups and relevant focus group facilitating skills, the SMEP and the characteristics of the participants. We have particularly rehearsed with the focus group topic guide before doing for real.

5.3.4.2 Focus groups in practice

The participants were invited to participate in the focus groups through telephone calls. The focus groups were taken place in a meeting room at out-patient department. The three focus groups lasted for 60 to 85 minutes. None was stopped due to time constraints or fatigue of participant. During the focus group, an observer was within the group to help taking notes of the group dynamics and contextual information. A debriefing with the moderator and the observer was done following each focus group, to review the salient messages and ambiguity captured in the process. The focus groups were audio-recorded to keep the full information for analysis (Joyce, 2008).

5.3.5 Sampling strategy for Focus Groups

5.3.5.1 Determining number of Focus Groups

Among all 50 recruited participants of the study, the 26 participants allocating to the SMG were eligible to participating in the focus groups. In this case, the focus groups aimed at exploring a narrow category of people, so fewer focus groups could be acceptable (Krueger, 1988). Even so, the number of focus group to hold is likely to be related to the different characteristics of participants reflected in selection. Barbour (2007) argued that even holding two focus groups with similar characteristics may gain firmer ground for the patterning of the data as long as they make as much comparison as possible. On the other hand, the participants in this study might share intense and lengthy experiences with their disease management, thus smaller focus group could possibly get more in-depth insights in this specific perception and experience (Krueger, 1988). In the perspective of a researcher, smaller group is more likely to pay closer attention to the type and content of interaction (Barbour, 2008). Therefore, three focus groups with each having four patients were conducted at T2 in this study. It is because when the third focus group was conducted, there were not many new codes appeared and data saturation was considered to have reached. After determining the number of focus groups, further concern here relates to the strategy for selecting participants who can give rise to data of relevance to the research aims.

5.3.5.2 Selecting participants for Focus Group

Given that this study was an embedded design, the focus group paid a less dominant and a supplementary part in the overall data collection. Hence, it was considerably adequate to drive the participant selection by the purpose and practical concerns of the study. In this case, purposive sampling was adopted and sampling strategies as such reflects diversity and provides the maximum possibilities for comparisons (Barbour, 2008). In terms of implementation, I purposively selected among the SMG participants by matching characteristics, for examples, age, gender, stage of severity

of the disease and family conditions, which are found to have some bearing on their experiences of living with COPD (Guthrie et al., 2001, Leung et al., 2002, Punekar et al., 2007). In this study, the education level of the participants was also taken into account as it can possibly affect his/her ability of receiving information from the SMEP. This approach to sampling formed a structure composing both male and female COPD patients at extreme age, from mild to severe stage of disease and encountering the disease independently or with family support. Therefore, 18 participants were selected from 23 participants of the experimental group who have completed the trial. The remaining five participants were not selected because they either bear the same background characteristics of the selected participants or have deficiency in hearing. 10 participants as well as one family member (wife of a participant) consented to participate in the three focus groups. Eight invited participants were lost due to three feeling sick, two were out of town, two were hospitalized and one was unavailable when the focus groups took place. The characteristics of the participants selected by purposive sampling are shown in table 2.

Table 2 Characteristics of participants of the focus groups

	Sex	
	Male	Female
Age < 60	--	2 +1*
61 to 70	5 (3 NA)	1 (1 NA)
71 to 80	2 (3 NA)	(1 NA)
COPD classification		
Stage II	1 (3 NA)	2 (1 NA)
Stage III	4 (1 NA)	1
Stage IV	2 (2 NA)	(1 NA)
Education level		
Illiteracy	--	(1 NA)
Primary	5 (5 NA)	3
Secondary	2 (1 NA)	--
Tertiary or above		(1 NA)
Living condition		
Live alone	--	1 (1 NA)
With partner or children	(2 NA)	1(1 NA)
With partner and children	7 (4 NA)	1
Total	7 (6 NA)	3 = 1* (2 NA)

NA : non attendance

* Family member

5.3.6 Characteristics of Focus Group Participants

The participants ranged from 47 to 74 of age and were at stage II to IV of COPD. Due to failure of recruiting an illiterate and tertiary educated participant, the focus group participants had primary to secondary level of education. The participants were either living alone, with a partner, or with both partner and children. They may share similar diverse concerns and issues in relation to family support in encountering disease management. In addition, a third party, a family member, has joined one focus group and she may potentially provide views on disease management from an informal caregiver's perspective.

5.3.7 Section Summary

In the qualitative strand, I argued for the use of focus groups to understand self-management, such a complex behaviour, and motivation in the interaction among the participants. Focus group topic guides were prepared with special attention of ensuring open discussion and group dynamic. I intentionally avoided myself to facilitate the focus groups so as to minimize bias and the invited moderator was given relevant training of running focus groups. Three focus groups were conducted. They consisted of 11 participants who were of diverse characteristics were purposively selected from experimental group to explore their experiences and perceptions of self-management.

5.4 Section Four Complex Intervention of the Experiment -- Self-management Education Programme

5.4.1 Introduction

The intervention of this study, namely SMEP, is a complex intervention and there is no 'standard' programme developed or run with well and widely recognition in any reported studies (Effing et al., 2007, Adams et al., 2007). The development of the protocol of SMEP has followed the MRC (2008) framework which rigorously provides guidance for developing and evaluating a complex intervention. This framework advised a sequential series of phases: 'Pre-Clinical' – initial theory exploration; Phase I - modelling; Phase II - exploratory trial; Phase III - definitive RCT or main trial; Phase IV - or long term surveillance. As mentioned earlier in methodology chapters, this study has undertaken the phase II of the complex intervention evaluation process where I can experiment with the intervention and evidence derived can support the theoretically expected treatment effect (MRC, 2000). The next section will present the process of developing and conducting the SMEP in this study.

5.4.2 Development of Self-management Education Programme

The SMEP consists of three components: 1) Self-management education workshop, 2) Patient handbook and 3) Telephone follow-up. The steps for establishing these components are addressed in four different stages as followed.

5.4.2.1 Preparation Stage – Programme development

5.4.2.1.1 Self-management Education Workshop

A protocol for the SMEP was developed based on the GOLD (2013) advice on education programme for COPD patients at different stage of severity and systematic review reporting about the structure of SMEPs (Effing et al., 2007, Monninkhof et al.,

2003). The protocol of the self-management education workshop was initiated and it comprised two main components: 1) COPD education and 2) self-treatment guidelines (or an action plan) (Refer to Figure 5). This figure demonstrated the structure and relationship of the topics of the workshop in accordance to the MRC framework for identifying the key relations among topics.

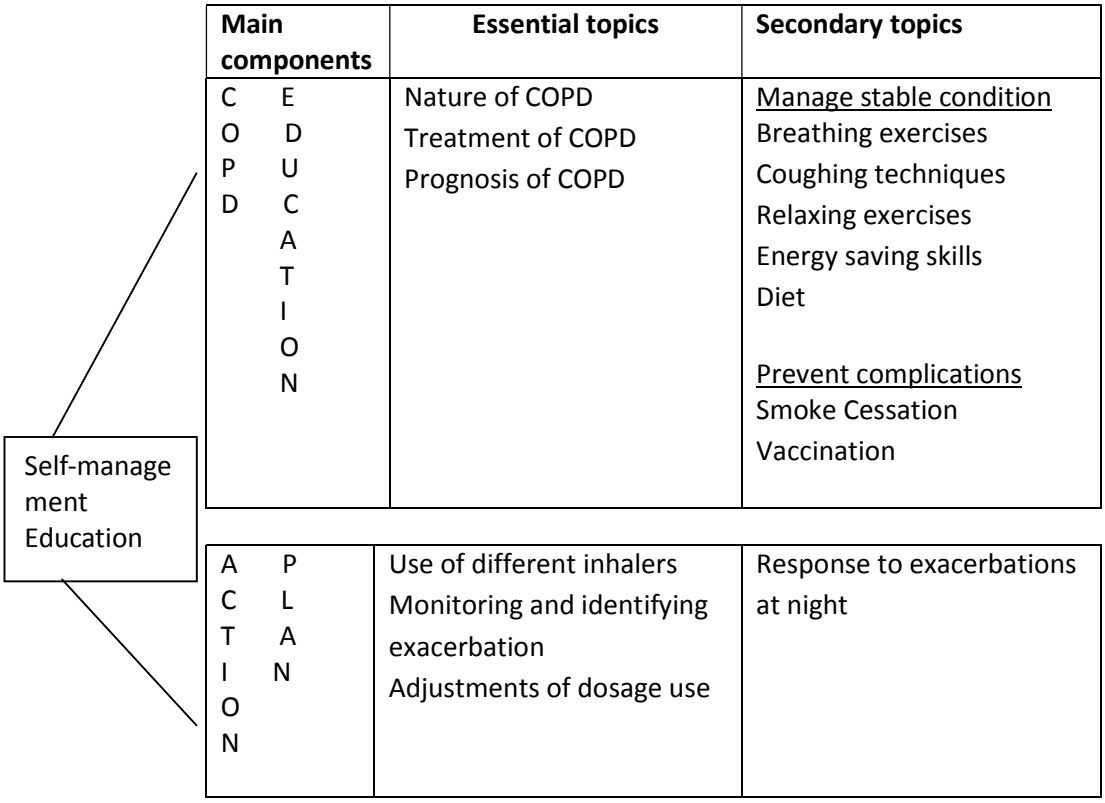


Figure 5. Interrelationship among the intervention components.

The sequence and method for the delivery of the topics were designed under the consideration of the theories of illness perception and self-efficacy beliefs. In regard of improving illness perception belief, the workshop has been designed to clearly identify the symptoms and aetiology of COPD (Identity and Cause), to stress its chronicity and possible reverse consequences (Timeline and consequences), and encourage the patients about the controllability of the disease (Control). To incorporate the self-efficacy belief in enhancing self-management, I planned the simple but essential mastery topics at the beginning session in order to bring success experience and avoid likely failing situations in the participants (performance

accomplishment); participant's successful experiences were shared among the group (vicarious experience); I shared scientific reports on positive impact of self-management of COPD patients (verbal persuasion); any improvement in oximetry parameters during pursed lips breathing was feedback to the participants to boost confidence in the intervention (physiological status) (Roberts et al., 2009, Bandura, 1989). These activities attempted to promote and strengthen the participants' outcome expectations and efficacy expectations for engaging in self-management.

5.4.2.1.2 Patient handbook

The patient handbook was developed according to the information included in the workshop (Appendix 14). Considering that the targeted participants were comparatively senior in age, the handbook was written in characters with large font, with lay expression and the support of instructive pictures and photographs in order to achieve a better understanding among the participants.

5.4.2.1.3 Telephone Follow-up

I collected the personal telephone number of all participants under their consent and informed them about the telephone follow-up during the six months observation period. Telephone calls were made to participants in SMG every other month to reinforce the teaching content and clarify queries of them. However, the participants of CG were given a courtesy phone call which is of no educational advice. They were only asked about some updates of their healthcare utilization and were not provided with any health education information in the call. Another aim of making placebo telephone follow-up was to get in touch with the control group participants to minimize drop out. Each telephone call lasts five to 15 minutes.

5.4.2.2 Pilot Stage – Programme Validation

5.4.2.2.1 Content Validity

Before the real implementation of the complex intervention in the experiment, content validity and pilot exercise were conducted on the initial protocol of the SMEP. In content validity, I invited two locally based respiratory physicians, one respiratory nurse, one nurse specialist in respiratory rehabilitation, one physical therapist, one dietician and one Traditional Chinese Medical physician to review the relevancy and the feasibility of the programme protocol. The experts were briefed about the definition of self-management and aims of the study, and they rated on the components against three choices : they are 1) relevant/feasible; 2) relevant but revision necessary/feasible but revision necessary; 3) irrelevant/infeasible. The content validity index (CVI) for the COPD education component was 0.99 (0.67~1.00) in appropriateness and 0.98 (0.67~1.00) in feasibility. For assessing the content validaity of action plan, although it is essential in SMEP by definition, the experts showed controversial opinions. Thus, an independent content validity has further been carried out by inviting all seven respiratory doctors of the study venue to review the appropriateness and feasibility of the action plan. Their response demonstrated a CVI of 0.77 (0.43~1.00) in appropriateness and 0.74 (0.29~1.00) in feasibility. Topics rated low content validity (0.29 and 0.43) include self-management of steriod and antibiotics usage respectively. The final action plan excluded these two content and only included the directive for adjusting short-acting bronchodilator (See appendix 15), then the overall CVI for the SMEP shows a high validity both in appropriateness (0.95, ranges from 0.67 to 1.00) and in feasibility (0.93, ranges from 0.67 to 1.00). In addition, alteration to the SMEP has been made according to the recommendation given by the experts, for instance, including recipe of Chinese home-made soup which is specifically for people with respiratory conditions and introduction of supplementary nutritious products (See Table 3).

5.4.2.2.2 Pilot testing

In the pilot exercise, four COPD patients were invited to attend the revised self-management education workshop. They commented that four 1.5-hour workshops running every other week were quite time-consuming. The paticipants

expressed no apparent difficulty in comprehending the teaching content and particularly appreciated the content of inhaler usage, breathing exercise and recipe of the Chinese home-made soup. In overall, the participants appreciated the workshop and the protocol of the workshop was finalized to be three 1.5-hour workshops running once every week so as to save the time of participants and enhance the smoothness of the progress.

Table 3. The combination and distribution of the topics of the self-management education programme pre- and post-validity testing

Before Validity Testing		**After Validity Testing**	
Workshop/ duration	**Content**	**Workshop/ duration**	**Content**
1 (1.5 hrs)	Topic 1–6 Information about nature of COPD Topic 7-11 Use of difference inhalers Topic 12 Monitoring and identifying exacerbations Topic 13 Recording of exacerbations	1 (1.5 hrs)	Topic 1–6 Information about nature of COPD Topic 7-11 Use of difference inhalers Topic 18 Action plan (short-acting bronchodilators administration only) Topic 27 Response to exacerbations at night Topic 12 Monitoring and identifying exacerbations Topic 13 Recording of exacerbations
2 (1.5 hrs)	Topic 14-17 Breathing exercises Topic 18 Action plan	2 (1.5 hrs)	Topic 14-17 Breathing exercises Topic 19-23 Coughing techniques Topic 24 Relaxing exercise Topic 25-26 Energy saving technique
3 (1.5 hrs)	Topic 19-23 Coughing techniques Topic 24 Relaxing exercise Topic 25-26 Energy saving technique Topic 27 Response to exacerbations at night	3 (1.5 hrs)	Topic 28-30 Diet and pulmonary health (including Chinese home-made soup) Topic 31 Smoking Cessation Topic 32 Vaccination Topic 33-35 Managing stable condition and preventing complications
4 (1.5 hrs)	Topic 28-30 Diet and pulmonary health Topic 31 Smoking Cessation Topic 32 Vaccination Topic 33-35 Managing stable condition and preventing complications		

5.4.2.3 Pre-implementation Stage - Facilitator Training

I, as a registered nurse and nursing educator in Macau, was the principle instructor of the workshop and two other nurses who have been experienced in respiratory care (eight years of experiences) participated as intervention agents in some sections of the workshops. An eight-hour training was carried out among the researcher and the intervention agents by rehearsing the programme protocol to assure inter-instructor reliability in the experiment.

5.4.2.4 Implementation Stage – Programme running

All participants in the SMG were invited to complete the SMEP by attending three self-management education workshops, getting a patient handbook and being arranged a telephone follow-up after the workshop. The workshops were taken place in an out-patient chronic illness center of the hospital where most participants were recruited. This center was about $100m^2$ and was particularly designed for health education purpose as it has been equipped with multimedia and projectors. The teaching content of the workshop was delivered in verbal and visual forms by means of lecturing, demonstration, re-demonstration and video watching. Each workshop was run in a group-based with four to six participants interacting with each other. Two participants were taught on an individual basis as they could not join the scheduled workshop due to personal reasons. For those who dropped some sections owing to unforeseen commitments, holidays, sickness and other reasons, they have been arranged to join in other groups and attend the missing section(s). The study did not interfere with participants' regular out-patient visit pattern. Participants who requested for assistance from their caregiver or family member in the workshop were allowed to be accompanied by appointed significant other(s). Oxygen, quick-relief medications and Ambu-bag were ready in the room for safety considerations. (Worth and Dhein, 2004, Kara and Aşti, 2004). Every participant was given a patient handbook which was referred to from time to time during the workshop.

5.4.3 Conventional Therapy

Participants allocated to the CG followed their routine visit to the physicians and received medicinal therapy which uses to relieve airway construction, suppress inflammation, coughing and sputum production. Prescribed medications used in Macau for relieving airway construction include short-acting β_2 agonists, short-acting anticholinergics, combined relievers, preventers (inhaled corticosteroids), long-acting β_2 agonists and combined preventers. In addition, oral theophylline for relieving wheezing and corticosteroids for relieving cough and sputum production and suppressing airway inflammation would have administrated if needed. For patients suffering from dyspnoea or hypoxia, oxygen therapy was given.

5.4.4 Section Summary

A SMEP was developed under the MRC (2008) framework for developing and evaluating complex intervention. As in a theoretical and modeling phase, both illness perception and self-efficacy beliefs were incorporated in the education programme development in order to enhance these two aspects when engaging in self-management. The SMEP comprises self-management education workshop, a patient handbook and telephone follow-up for six months after the workshop. The protocol of the self-management education workshop has high content validity in COPD education component, whereas only bronchodilators management showed high validity and was included in the action plan component of the workshop. The workshop has been piloting on four COPD patients and it was in overall understandable and acceptable among them. The finalized SMEP was performed on the SMG participants while the control group received conventional therapy which included routine medical treatment for COPD. After conducting the intervention, relevant assessments were done to evaluate its impact on the participants. The next section will present the methods for analyzing and interpreting data collected from the quantitative and qualitative strands, and the approach for mixing these data.

5.5 Section Five Data Analysis

5.5.1 Introduction

This section covers the technical aspects of analyzing and interpreting the data collected. To analyzing quantitative data, SPSS 13.0 software was used to produce descriptive and inferential statistics. On the other hand, the qualitative data was viewed as subjects' expression of unique experiences which embedded with meanings. Thematic analysis based on a constructionist approach was adopted to analyze the focus groups and interpret the emerging themes (Silverman, 2011). Thus, in this section, the quantitative data analysis will be addressed first, followed by qualitative data analysis and the mixing of quantitative and qualitative data will be covered in the last part of this section.

5.5.2 Quantitative Data Analysis

All numeric data was assessed for pattern of distribution using the skewness and kurtosis statistics or Kolmogorov-Smirnov *Z* test (De Vaus, 2002). When distribution of the data measurement was normal, parametric methods were used where meeting the assumption for execution including independent t-test (*F*) and Pearson's product moment correlation coefficient (Pearson's correlation, *r*). When distribution was not normally distributed, non-parametric methods were used accordingly including Mann-Whitney U-test (*U*), Wilcoxon signed rank test (*Z*) and Spearman's rank-order correlation coefficients (spearman's correlation, rho). For analyzing categorical data, I used chi-square (χ^2) to examine the relationship between variables by assessing the statistical significance of a contingency table (Argyrous, 2005). Statistical significance was set at the level of $p < 0.05$. The following paragraphs will give a detailed presentation of the specific statistical methods used in relation to three aspects namely the demographic data, primary and secondary outcomes.

5.5.2.1 Demographic data analysis

Descriptive analysis demonstrated the demographic conditions as well as the comparable properties of the participants. Mean, standard deviation (SD), frequency as well as percentage were computed to demonstrate the participants' demographic characteristics and clinical characteristics. To compute the baseline comparison of both SMG and CG, I did independent t-test on normally distributed clinical variables, for instances, 'age', 'post-BD FEV_1', 'post-BD FEV_1% predicted' and 'number of concomitant diagnosis', while I did Mann-Whitney U-test on non-normally distributed variables, for instances, 'sex', 'years of diagnosis', 'amount of smoking in pack years', 'mastery rate of all inhalers', 'amount of smoking in pack year', 'number of unplanned visit to MD or ER' and 'days of hospitalized'. Nominal or ordinal variables such as 'sex', 'education level', 'smoking habit', 'working condition', 'marital status', 'living condition', 'medical expenses', 'long-term treatment', 'frequency of using SABA' and 'flu vaccination' were analyzed with chi-square to compare between SMG and CG, of which Yates' continuity correlation was particularly used in comparing variables with cells having five to nine cases and Fisher's exact test used in comparing variables with cells having less than five cases (Plichta and Garzon, 2009).

5.5.2.2 Primary and secondary end outcomes analysis

This paragraph presents statistical methods which possibly provide findings capturing research aim one and two covering the primary and secondary outcomes of this study. Firstly, to compare the scores of self-efficacy, illness perceptions, mastery rate of inhalation skills, pulmonary function, and health-related quality of life between SMG and CG, independent t-test or Mann-Whitney U-test was utilized. Both tests can be used when the grouping variable is dichotomous, the measures of each value of the variable constitute an independent random sample and the variable is an interval or ratio, while Mann-Whitney U-test can also be used when the variable is ordinal and the total sample size is at least eight (Plichta and Garzon, 2009). These comparisons were performed at T0 and T2 to examine for statistical difference in

post-test outcomes between the two groups in compared with their baseline assessment. Secondly, paired t-test or Wilcoxon signed rank test was utilized to compare the above scales between T0 and T2 or T1 and T2 within groups. The paired t-test can be used with confidence, and there is a lower risk of error if just a few assumptions are violated, the sample size is large, the data are not too skewed, and there is a fairly large range of values. The Wilcoxon matched-pairs test has fewer assumptions and can be used with ordinal-, interval-, or ratio-level data. It assumes that there are at least five paired measures to compare (Plichta and Garzon, 2009). Although these tests involve multiple testing that may lead to accuracy problems, the testing variable can be measured on the same person at two different points in time. Therefore, they can examine the effects of the intervention on SMG in compared with CG. Thirdly, Pearson's correlation can identify factors positively or negatively associated with the participants' outcomes. Provided that the total and all subscales scores of IPQ and CSES were normally distributed, Pearson's correlation was run to assert relationship between the illness perception and self-efficacy of the participants. Moreover, to further examine factors associating with the illness perception, self-efficacy and health-related quality of life of the participants, Pearson's correlation or spearman's correlation was computed. This examined their association with the demographic characteristics of the participants. In summary, these tests possibly revealed the effects of the SMEP if statistical significances were found between groups or within groups in time, given that homogenous features were identified in both groups and all external factors were held constant.

5.5.3 Qualitative Data Analysis

Focus group, as a qualitative method of data collection, is not intended to infer, generalize or make statement about the population, but to understand and provide insights about how people perceive a situation (Krueger, 1988). In particular, it anticipates to making significant meaning construction among participants on the focused topic. In the following, I discuss the data analysis of focus groups in the view of the choice of approach for analysis and how did I conduct the analysis.

5.5.3.1 Understanding Data Analysis for Focus Groups

Conventional approaches utilized for analyzing focus group were content analysis and thematic analysis. Although many claimed the homogenous nature of both approaches, qualitative research experts tried to categorize them under the name of quantitative content analysis and qualitative thematic analysis (Silverman, 2011). Morgan (1997) upheld that descriptive counting in content analysis is especially useful to make comparisons within and across focus groups, with Frankland and Bloor (1988) added more weight to content analysis by stating that systematic counting prevents impressionistic assumptions (Frankland and Bloor, 1988). On the contrary, others argued that content analysis simply gives access to how people talk about their experiences or view of the world while thematic analysis aims to ground interpretation of meaning from how people lived in the social world (Braun and Clarke, 2006, Silverman, 2011). In contrast, Silverman (2011) tried to infer the lost sight of the whole with thematic analysis and assert the superiority of constructionist approach over thematic analysis by grasping the process as well as content within the focus. Nonetheless, I found that this attempt of making distinct differentiation between thematic analysis and constructionist analysis has overlooked the constructionist stance bearing in the thematic approach. Thematic analysis is, in essence, sharing the stance of the constructionist paradigm which views how events, realities, meanings, experiences, and it also explores the product of a range of discourses and interaction operating within society or between individuals (Braun and Clarke, 2006). Group dynamic demonstrates how accounts are articulated, censured, opposed and changed through social interaction (Barbour and Kitzinger, 1999). It was persuasive to think that thematic analysis conducted within a constructionist stance is not merely dependent on quantifiable measures or patterning response or meaning within the data set, it also focuses on the socio-cultural contexts and structural conditions by taking both salient and latent themes into consideration.

In this line of reasoning, I adopted thematic analysis in this study to analyze the focus group data. Focus group data, in this sense, was seen to tap into the process of social knowledge formation. I, as a researcher, utilized thematic analysis to examine

how such knowledge emerged in group interactions within a specific context. Group interactions in the focus groups present a social environment, so conducting focus group data analysis should avoid lifting comments out of context and out of sequence and should capture when and how participants modify or even reverse their positions in the interacting process (Krueger, 1988). Knowledge developed this way in regard of SMEP should largely be the constructs of negotiation and interpretation of meaning between the participants and me, as the researcher. After determination of employing thematic analysis for analyzing the focus groups I will look into the concrete steps of implementation in the next paragraph.

5.5.3.2 Conducting Focus group data analysis

5.5.3.2.1 Transcribing and Coding

Analyzing focus groups, resembling other qualitative approaches, has to transcribe the focus group recordings, and then proceed to coding, categorizing and theme development. As thematic analysis captures not only what people talk about things, but also how people talk through it and their interaction in that specific context, I decided to transcribe the three focus groups in the discourse level which detains the pitch and volume of the participants' speech and the dynamic of the group (Gibbs, 2007) (Transcript symbols and sample of transcript refer to appendix 17 and 18 respectively). This formed the foundation for further constructionist thematic analysis. Since the focus groups were conducted in Cantonese, they have been translated into English by independent translator who can comprehend both Cantonese and English fluently. Then, analysis started with in-vivo coding which is a process of attuning myself to the participants' language, perspectives, and worldviews through reading the transcripts and the tapes (Saldana, 2009). After finishing the initial coding, the coding scheme has been examined; evaluated for meaning, trends, and relationships; and refined by clarifying the terminology and definitions to ensure dependability (Bryman, 2008).

5.5.3.2.2 Developing Categories and Theme

Coding further enables the organization and grouping of similar coded data into categories and thus identifies a pattern (Saldana, 2009). I compared the various categories with each other and some consolidated in a way that I felt the "meaning" of the data was transcended and I progress to a more general and more abstract construct, namely a theme. A theme is a phrase or sentence that distinguishes what a unit of data tells and/ or means (Saldana, 2009). Theme and categories were re-examined by repeatedly comparable reflection on participants' meanings and the patterned codes. Reflection was done by drawing the context in the analysis in order to grasp a full view of the phenomenon. Barbour depicted this concept as follows:

> *"Rather than simply seeking to identify the views of the various participants, attention to the context in which comments are made and the exchanges between group members allows us to develop an analysis that takes account of the complexities involved, including the explanations, justifications and tentative hypotheses advanced by people taking part in our research."* (Barbour, 2007) (Barbour, 2007, P. 136)

As I am the only researcher in the study, inter-coder agreement was not the main issue in the study. An academician who is expert of qualitative research has helped to review a sample of transcribed data, the coding scheme and themes identified. This process assured the confirmability and trustworthiness of the findings (Bryman, 2008).

5.5.3.2.3 Reflexivity in Analyzing Process

Group is the main unit of analysis where captures the group interaction combining both observation of interaction and access to the verbal expression of the participants (Krueger, 1988, Barbour, 2007). After then, I interpreted the findings by stepping back from the detailed results and advancing their larger meaning in view of the research problems, questions in a study, the existing literature and personal experiences (Creswell and Plano Clark, 2011). On the contrary, the relationship between the researcher and the researched may be challenged by accused of affecting the practical adequacy of knowledge claims. However, there was argument that thinking is never emotion-free. Emotion should not or could never be partitioned from reasoning, but

should be understood and reflected on during research process (Bondi, 2005). Reflexivity is identified as an anchor of a researcher in self-sensations and self-knowledge and is defined by Gray as follows :

> "*Research reflexivity, predominantly understood as the researcher's engagement with her own positioning in relation to the world she is researching, and/or the self-conscious writing up of research as itself an act of representation, is currently invoked as a way of addressing the presence of the knower in the known and vice versa* (Gray, 2008).
> .

In this case, by applying reflexivity in data interpreting process, here I demonstrate an inquiry on the formative conditions all along the process by self-consciously addressing my biographical relationship to the topic and the instability between the research text and the object of the study in terms of divergent voices or contradiction to potential readings. This enables me to have access to opportunities to discuss emotional experiences of research in confidence and non-prescriptively (Liz Bondi 2005). I believe reflecting on my own emotional experiences as such serves to develop rich understandings of what it is. According to Reinharz (1997), the researcher should examine the various aspects of 'selves' in that specific research situation (Reinharz, 1997).

My biographical relationship to the topic:

- Research-based selves – being a PhD student, executor of the intervention, being the contact person of the participants throughout the process, being a registered nurse with respiratory nursing experience.
- Brought selves – being Macanese, being a daughter of a man who has no COPD but has smoked for 40 years, being a nurse with 10 years experiences in teaching and practicing respiratory nursing in Macau.
- Situationally created selves – being a nurse not attached to the hospital, being a listener, being a researcher, being an instructor.

Being the researcher as well as intervention executor of this study, I acknowledge that I had the advantage of better understanding the background and contextual

characteristics of the participants. However, my personal affection for the success of the intervention might have biased the interpretation on the participants' responses. The participants might accept to be interviewed with the motivation of anticipating for more health information or to help the researcher by showing appreciation for the free 'service' (workshop).

To conclude, I have considerably discussed the deliberation of the choice for the approach of focus group data analysis. Also, I have delineated the naturally social interactive form of focus group and how does this element integrate into the analyzing process. It is apparent that data analysis of focus group is by no means separated from the design of the study and the epistemological stance employed in the study. Therefore, I employed thematic analysis which bore an underlying constructionist ground to analysis the focus groups. After then, it is critical to appropriately combine the qualitative findings with the quantitative results. The approach of data mixing will be provided in the following section.

5.5.4 Mixing of Quantitative and Qualitative data

As an embedded design with a combination of concurrent and sequential approaches, data analysis was accordingly conducted with different avenues in different phases. Integration of two sets of different forms of data and their results in a meaningful way can be challenging, it is important to articulate the strategies employed (Bryman, 2007). In the concurrent phase, the quantitative and qualitative data were analyzed separately as they answered different research questions (Creswell and Plano Clark, 2011). In the sequential phase, the secondary qualitative data was collected after the acquiring the quantitative results in the concurrent phase. Connected mixed methods data analysis was considered as a specific strategy for interpreting sequential results. In this strategy, the analysis of the first data set was connected to data collection in the second data set. Analysis was focus on how the second data set could build on what was learned in the quantitative data set (Creswell and Plano Clark, 2011). This involved mixed methods interpretation which looked across the quantitative results and the qualitative findings and made an assessment of how the information

addressed the mixed methods question in the study. This mixed methods interpretation is called "meta-inferences" and its definition is:

> *"Inferences in mixed methods research are conclusions or interpretations drawn from the separate quantitative and qualitative strands of a study as well as across the quantitative and qualitative strands, called meta-inferences."* (Creswell and Plano Clark, 2011, P. 212)

Applying the definition to the present study design, meta-inferences referred to the notion that the follow-up qualitative data would provide a better understanding of the problem than merely using the quantitative results. Meta-inference should be drawn at the end of the study and included in the larger interpretation in the discussion and conclusion of the study (Creswell and Plano Clark, 2011). Moreover, regarding addressing the mixed methods question, meta-inferences needed to be responsive to answering a question such as: To what extent do the qualitative follow-up findings explain the participants' reactions to self-management intervention? It was to connect the primary and secondary results in a way to give an interpretation for responding to the question.

5.5.5 Section Summary

This section has addressed the approaches for analyzing the quantitative and qualitative data collected in this study. Distribution of data was carefully examined to identify the use of parametric or non-parametric statistical methods. The quantitative data was analyzed with SPSS software to examine the baseline assessment with descriptive statistics and to differentiate the impact of the intervention between SMG and CG with inferential statistics. In terms of qualitative data analysis, thematic analysis based on a constructionist approach was employed to analyze and interpret the focus groups. The quantitative and qualitative findings were connected to produce meta-inferences that responded to answering the proposed mixed methods questions.

5.6 Summary

This chapter is divided into five sections which provide a detailed account of embedded design associated with experimental design, complex intervention and mixed methods. In section one, a pragmatic foundation was embraced to accommodate mixed methods in this study as pragmatism was flexible enough to respond to both confirmatory and exploratory research questions of the practical context suggested. An exploratory RCT with mixed methods (quantitative method and qualitative method) was employed with reference to MRC (2008) framework for developing and evaluating complex intervention. These methods were mixed in concurrent and sequential approaches during the process data collection. In section two, randomized sampling in block randomization approach was proposed for the RCT and purposive sampling was adopted for the qualitative strand. In section three, the methods of data collection were presented in terms of primary outcomes (illness perception, self-efficacy and inhaler usage technique) and secondary outcomes (post-BD FEV_1, post-BD FEV_1% predicted, frequency of using rescue medication and healthcare utilization, generic and disease-specific HRQoL) and supplemental data (focus groups). Measures used for assessing primary and secondary outcomes were delineated with respect to the construct, validity and reliability of each measure. On the contrary, focus group is defended for exploring the subjective experiences of self-management of the participants. In section four, the process of the development of the intervention, SMEP, was introduced in accordance with the MRC guideline, and its expert validity and pilot exercise were addressed. The validated SMEP was allocated to SMG while conventional therapy was given to the CG. In section five, the rationale for the application of descriptive and inferential statistics for the quantitative data was given, while thematic analysis with a constructionist ground for analyzing focus groups was explained. Subsequently, meta-inferences could be produced from the connection and interpretation of both sets of findings. In the next chapter, the quantitative results will be presented in respect of primary outcomes and secondary outcomes of this study.

Chapter Six Quantitative Results

6.0 Introduction

The study examined the SMEP for COPD patients in Macau. The results are presented in four parts in this chapter. Part one presents the basic characteristics of the samples in terms of demographic data and clinical data to give an overview of the sample recruited. This part also includes the comparison of these basic characteristics between the SMG and CG. Part two presents results of the primary end outcomes including illness perception, self-efficacy and inhaler technique, and secondary end outcomes including pulmonary function, healthcare utilization, generic HRQoL and disease-specific HRQoL. Significant differences between the SMG and CG and within groups at pre- and post-test are displayed in relevant tables to indicate the effects of SMEP on these measures. Part three presents the bivariate correlation statistics of illness perception and self-efficacy to examine the relationship among concepts in these two beliefs adopted in the theoretical framework of the study. Part four presents the inter-relationship of basic characteristic variables and significant variables of the above two beliefs by using a correlation matrix. This demonstrates factors which are positively or negatively associated with the illness perception and self-efficacy of participants.

6.1 Part One Sample characteristics

6.1.1 Demographic characteristics

The overall characteristics of the recruited 50 participants are showed in table 4. The mean age of the participants was 67.9 (SD 10.2) and it ranged from 44 to 87 years. 74% (37 participants) were male, 68% (34 participants) were either ex-smoker or current smoker whose amount of smoking made up a mean of 13.2 pack years (SD 25.7). In relation to educational level, the majority of the participants was either in primary level (52%, 26 participants) or illiterate (14%, 7 participants). 78% (39 participants) of them had no working experiences at all, were retired, unemployed or lost working ability due to disease(s). Most of the participants (74%, 37 participants) were married or were having a stable partner and 84% (42 participants) were living with partner and children or either side. Regarding the medical expenses, most participants adopted a mix of public medical coverage (72%, 36 participants) and self-payment (72%, 36 participants).

6.1.2 Clinical characteristics

Among all participants, 52% (26 participants) were diagnosed COPD while the others were either diagnosed of chronic bronchitis (32%, 16 participants) or emphysema (10%, 5 participants), of which 6% (3 participants) previously diagnosed asthma in their medical record were found to be fulfilling the diagnosis of COPD according to the GOLD's (2008) spirometric classification of COPD in this study. Based on the GOLD's classification of severity of COPD, 42% (21 participants), 42% (21 participants) and 16% (8 participants) of the participants belonged to stage II, III and IV respectively. The average year of being diagnosed of COPD was 8.4 (SD 8.6) (range 1.0-30.0). Their post-bronchodilator FEV_1 % predicted was averagely 47.9% (SD 16.5) (range 15.0-79.0) with an associated mean post-bronchodilator FEV_1/FVC at 49.1 (SD 11.0) (range 27.7-69.8). 72% (36 participants) had at least one concomitant disease and the mean number of concomit-

Table 4 Basic characteristics of the sample

	Mean (n = 50)	SD	Frequency	%
Demographic characteristics				
Sex				
Male			37	74
Female			13	26
Age	67.9	10.2		
Education level (n = 42)				
Illiteracy (Non-educated)			7	14.0
Primary level			26	52.0
Secondary level			15	30.0
Tertiary level or above			2	4.0
Smoking habit				
Non-smoker			16	32.0
Current smoker			12	24.0
Ex-smoker			22	44.0
Amount of smoking in pack year (SD)	13.2	25.7		
Working condition				
Retired or Never work			24	48.0
Currently working			11	22.0
Unemployed			5	10.0
Lost working ability due to disease			10	20.0
Marital status				
Single			3	6.0
Married			37	74.0
Divorced or widow			10	20.0
Living condition				
Live alone			5	10.0
Living with partner or children			18	36.0
Living with partner and children			24	48.0
Living with relatives or friends			3	6.0
Medical expense				
Public medical coverage			36	72.0
Self-payment			36	72.0
Paid by patients' families			14	28.0
Medical insurance			2	4.0
Charity support			9	18.0
Others			1	2.0

Table 4 Basic characteristics of the sample (Continued)

	Mean (n = 50)	SD	Frequency	%
Clinical characteristics				
Diagnosis				
Emphysema			5	10.0
Chronic Bronchitis			16	32.0
COPD			26	52.0
Others			3	6.0
COPD Classification				
Stage II			21	42.0
Stage III			21	42.0
Stage IV			8	16.0
No. of years of being diagnosed	8.39	8.62		
Long-term treatment for respiratory condition			40	80.0
Pulmonary function				
Post BD FEV_1	1.10	0.51		
Post BD FEV_1% predicted	47.9	16.5		
Number of concomitant diagnosis	1.18	0.98		

-tant disease was 1.18 (SD 0.98) (range 0 – 4), and from the most common one to the least one, they were cardiovascular disease, skeletal-muscular disease, endocrine disease, urinal disease, gastroenterological disease, ophthalmological and otorhinolaryngological disease respectively. 20% (10 participants) was not treated for their respiratory conditions.

6.1.3 Baseline characteristics of experimental group and control group

Baseline characteristics of the participants (26 participants in SMG and 24 in CG) are presented in Table 5. Although the SMG showed a higher percentage of females (76.9%, 10 participants) than CG (23.1%, 3 participants), Fisher's test did not show significant difference (p=0.054). Another potential factor influencing the effects of the intervention could be the treatment received by the participants, here in table 6 indicates the participants' treatment in terms of the severity of the disease for reference. For all the other variables, both groups did not show statistical difference

Table 5 Baseline characteristics of the participants in SMG and CG

	SMG (*n* = 26) (%)	CG (*n* = 24) (%)	Statistics $X^2/F/U$	*P*-value
Number of patients				
Before intervention (T0)	26 (52.0)	24 (48.0)		
6 months after intervention (T2)	23 (54.8%)	19 (45.2%)		
Demographic characteristics				
Sex				0.05
Male	16 (61.5)	21 (87.5)		
Female	10 (38.5)	3 (12.5)		
Age X̄ (SD)	67.4 (10.5)	68.5 (10.1)	0.02	0.70
Education level (*n* = 42)			0.28	0.96
Illiteracy (Non-educated)	4 (15.4)	3 (12.5)		
Primary level	14 (53.8)	12 (50.0)		
Secondary level	7 (26.9)	8 (33.3)		
Tertiary level or above	1 (3.8)	1 (4.2)		
Smoking habit			0.69	0.71
Non-smoking	9 (34.6)	7 (29.2)		
Current smoker	5 (19.2)	7 (29.2)		
Ex-smoker	12 (46.2)	10 (41.7)		
Amount of smoking in pack year(SD)	10.8 (25.5)	15.9 (26.1)	1.33	0.49
Working condition			1.51	0.68
Retired or Never work	13 (50.0)	11 (45.8)		
Currently working	4 (15.4)	7 (29.2)		
Unemployed	3 (11.5)	2 (8.3)		
Lost working ability due to disease	6 (23.1)	4 (16.7)		
Marital status			2.95	0.23
Single	3 (11.5)	0 (0.0)		
Married	18 (69.2)	19 (79.2)		
Divorced or widow	5 (19.2)	5 (20.8)		
Living condition			3.52	0.32
Live alone	2 (7.7)	3 (12.5)		
Living with partner or children	8 (30.8)	10 (41.7)		
Living with partner & children	13 (50.0)	11 (45.8)		
Living with relatives or friends	3 (11.5)	0 (0.0)		

Table 5 Baseline characteristics of the participants in SMG and CG (Continued)

	SMG (n = 26) (%)	CG (n = 24) (%)	Statistics $X^2/F/U$	P-value
Medical expense				
Public medical coverage	17 (65.4)	19 (79.2)		
Self-payment	20 (76.9)	16 (66.7)		
Paid by patients' families	8 (30.8)	6 (25.0)		
Medical insurance	1 (3.8)	1 (4.2)		
Charity support	8 (30.8)	1 (4.2)		
Others	1 (3.8)	0 (0.0)		
Clinical characteristics				
Diagnosis			1.32	0.72
Emphysema	3 (11.5)	2 (8.3)		
Chronic Bronchitis	7 (26.9)	9 (37.5)		
COPD	15 (57.7)	11 (45.8)		
Others	1 (3.8)	2 (8.3)		
COPD Classification			0.40	0.82
Stage II	12 (46.2)	9 (37.5)		
Stage III	10 (38.5)	11(45.8)		
Stage IV	4 (15.4)	4(16.7)		
No. of years of being diagnosed	7.2 (6.2)	9.7(10.6)	6.85	0.31
Pulmonary function				
Post BD FEV_1	1.06 (0.46)	1.13 (0.55)	0.67	0.63
Post BD FEV_1% predicted	49.2 (17.3)	46.6 (15.8)	0.41	0.59
Number of concomitant diagnosis	1.1 (1.1)	1.3 (0.9)	0.06	0.45
Under long-term treatment for respiratory condition	19 (73.1)	21 (87.5)		0.29
Inhalers used				
MDI	17	14		
MDI + Spacer	4	5		
Turbuhaler	3	3		
Accuhaler	7	3		
Handihaler	5	5		

Table 5 Baseline characteristics of the participants in SMG and CG (Continued)

	SMG (*n* = 26) (%)	CG (*n* = 24) (%)	Statistics $X^2/F/U$	*P*-value
Rescue medication and Health care utilization in past 6 months:				
Frequency of using SABD			291.00	0.65
- *Never use*	14 (58.3)	14 (58.3)		
- *1-2 times/week*	2 (7.7)	2 (8.3)		
- *2-7 times/week*	3 (11.5)	2 (8.3)		
- *Once/ day*	0 (0.0)	2 (8.3)		
- *> once/ day*	7 (26.9)	4 (16.7)		
No. of unplanned visit to MD or ER (SD)	2.65 (3.7)	2.42 (4.0)	0.00	0.83
Days of hospitalized (SD)	6.62 (8.5)	4.96 (9.8)	0.00	0.53
Flu Vaccination	13 (56.5)	10 (43.5)		0.58

* Median (95% Confidence interval)

Table 6 The treatment that participants received at pre-intervention assessment

Treatment received		Stage II		Stage III		Stage IV	
		CG (%)	SMG (%)	CG (%)	SMG (%)	CG (%)	SMG (%)
Short-acting bronchodilator	Yes	3 (25.0)	4 (50.0)	6 (60.0)	7 (63.6)	4(100.0)	2 (50.0)
	No	9 (75.0)	4 (50.0)	4 (40.0)	4 (36.4)	0 (0.0)	2 (50.0)
Mixed short-acting bronchodilator	Yes	0 (0.0)	1 (12.5)	0(0.0)	0 (0.0)	1 (25.0)	0 (0.0)
	No	12 (100.0)	7 (87.5)	10(100.0)	11(100.0)	7 (75.0)	4 (100.0)
Long acting bronchodilator	Yes	1 (8.3)	1 (12.5)	2 (20.0)	1 (9.1)	2 (50.0)	3 (75.0)
	No	11 (91.7)	7 (87.5)	8 (80.0)	10(90.9)	2 (50.0)	1 (25.0)
Mixed preventers	Yes	4 (33.3)	0 (0.0)	5 (50.0)	6 (54.4)	2 (50.0)	2 (50.0)
	No	8 (66.7)	8 (100.0)	5 (50.0)	5 (45.5)	2 (50.0)	2 (50.0)
Inhaled steroid	Yes	0 (0.0)	0 (0.0)	1 (10.0)	0 (0.0)	1 (25.0)	0 (0.0)
	No	12 (100.0)	8 (100.0)	9 (90.0)	11(100.0)	3 (75.0)	4(100.0)
Oral steroid	Yes	2 (16.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
	No	10(83.3)	8 (100.0)	10(100.0)	11(100.0)	4(100.0)	4(100.0)
Oral bronchodilator	Yes	2 (16.7)	5 (62.5)	7 (70.0)	7 (63.3)	3 (75.0)	3 (75.0)
	No	10 (83.3)	3 (37.5)	3 (30.0)	4 (30.0)	1 (25.0)	1 (25.0)
IV steroid	Yes	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (12.5)	0 (0.0)
	No	12 (100.0)	8 (100.0)	10(100.0)	11(100.0)	7 (87.5)	4(100.0)

in terms of age, diagnosis, pulmonary function, staging of disease, number of concomitant disease, smoking habit, education, rescue medication and health care utilization and flu vaccination received in past 6 months before the trial. I could assume that both groups were well matched and the participants of the two groups probably came from the same population and were randomly allocated into two groups. This minimized the risk of committing type II error and the two groups could be presumed as comparable in the trial.

6.2 Part Two Primary outcomes and Secondary outcomes

6.2.1 Primary outcomes

6.2.1.1 Illness Perception

6.2.1.1.1 Identity Dimension

The illness perception outcomes are demonstrated in three sections which include identity dimension, illness representation dimension and causal dimensions respectively. Firstly, the mean score for the illness identity dimension was 4.69 (SD=2.63) with the maximum of 11.0 (Table 7). Among the given 13 symptoms, the most often identified symptom was breathlessness (98%, 48 participants), followed by sleeping difficulties, fatigue and loss of strength, etc. In the meantime, the participants also identified pain (16.3%, 8 participants) and stiff joints (14.3%, 7 participants) as the identity of their COPD condition.

Table 7 Identity dimensions perceived by COPD patients

	Range	Mean (SD)	Min	Max	Believed to be related to COPD (n = 49)	%
Identity subscale	0-13	4.69 (2.63)	0.0	11.0		
Symptoms						
Pain					8	16.3
Sore throat					14	29.6
Nausea					9	18.4
Breathlessness					48	98.0
Weight loss					22	44.9
Fatigue					30	61.2
Stiff joints					7	14.3
Sore eyes					2	4.1
Headache					8	16.3
Upset stomach					5	10.2
Sleeping difficulties					31	63.3
Dizziness					9	18.4
Loss of strength					25	51.0

6.2.1.1.2 Illness Representations

Table 8 Comparison between experimental and control group on illness representations dimension at T0 and T2.

Scale (range 1-5)	T0 Mean (SD)		*F* (*p*-value)	T2 Mean (SD)		*F* (*p*-value)
	SMG (n = 26)	CG (n = 24)		SMG (*n* = 23)	CG (n = 19)	
Identity(range1-14)	4.36 (2.61)	5.09 (2.67)	0.05(0.83)	5.00 (3.66)	6.11 (3.23)	1.07(0.31)
Timeline	3.49 (0.84)	3.43 (0.91)	0.02(0.89)	3.90 (0.93)	3.81 (0.79)	0.07(0.79)
Consequences	3.43 (0.68)	3.12 (0.76)	1.17(0.29)	3.40 (0.96)	2.94 (0.69)	2.77(0.10)
Personal control	3.27 (0.62)	3.40 (0.76)	1.04(0.31)	3.28 (0.72)	3.06 (0.77)	0.15(0.70)
Treatment control	3.34 (0.51)	3.21 (0.69)	1.45(0.24)	3.12 (0.75)	3.38 (0.74)	0.03(0.87)
Illness coherence	2.87 (0.74)	2.85 (0.79)	0.00(0.98)	2.73 (0.96)	2.76 (0.84)	0.36(0.55)
Timeline cyclical	3.42 (0.70)	3.45 (0.96)	2.14(0.15)	3.60 (0.86)	3.36 (0.74)	0.58(0.45)
Emotional representations	3.27 (0.85)	3.19 (0.94)	0.69(0.41)	3.18 (0.99)	2.89 (0.98)	0.37(0.55)

Table 9 Comparison of median differences in illness representations between T0 and T2.

Subgroup (range 1-5)	SMG Median (range#)		*Z* *p*-value	CG Median (range#)		*Z* *p*-value
	T0 (n=25)	T2 (n=23)		T0 (n= 23)	T2 (n=18)	
Identity (range1-14)	4.00 (2.00-6.00)	4.50 (1.00-8.50)	-0.88 0.38	5.00 (3.00-7.00)	5.00 (4.75-7.25)	-1.86 0.06
Timeline	3.67 (2.67-4.17)	4.00 (3.50-4.71)	-2.47 *0.013**	3.50 (2.67-4.17)	4.08 (2.96-4.54)	-1.84 0.06
Consequences	3.67 (3.00-3.83)	3.58 (2.29-4.07)	-0.29 0.78	3.00 (2.50-3.83)	2.67 (2.50-3.67)	-0.22 0.83
Personal control	3.33 (2.67-3.75)	3.33 (2.67-3.71)	-0.14 0.89	3.67 (2.83-3.83)	3.00 (2.33-3.75)	-2.43 *0.015**
Treatment control	3.20 (3.00-3.90)	3.20 (2.80-3.60)	-1.11 0.27	3.20 (2.80-3.80)	3.50 (2.70-4.00)	-0.24 0.81
Illness coherence	3.00 (2.40-3.50)	2.90 (2.00-3.45)	-0.94 0.35	2.80 (2.40-3.60)	2.40 (2.15-3.60)	-0.52 0.60
Timeline cyclical	3.50 (3.00-3.75)	3.50 (3.00-4.25)	-0.90 0.37	3.50 (3.00-4.25)	3.50 (2.69-4.06)	-1.03 0.30
Emotional representations	3.33 (2.58-4.00)	3.25 (2.33-3.88)	-0.09 0.93	3.17 (2.33-3.83)	2.50 (2.00-3.83)	-0.69 0.49

Interquartile range; * *p*-value < 0.05

According to Weinman and colleauges (1996), the mean scores for each subscale can be assessed with the neutral point of 3. Hence, the sample of this study had six subscales ('Timeline acute/chronic', 'consequences', 'personal control', 'treatment control', 'timeline cyclical' and 'emotional representations') with mean scores greater than 3 and one subscale ('illness coherence') lower than 3. Independent t-test showed that there was no significant difference at T0 and at T2 between the SMG and the CG (Table 8). On condition that the total number of paired cases is less than 30, Wilcoxon signed ranks tests rather than paired t-tests are appropriate to determine whether there were any differences between the median scores at T0 and T2 for each group (Plichta and Garzon, 2009). Results revealed that scores on most of the eight IPQ-R subscales had remained unchanged, however, there was a significant increase in the median score in 'timeline acute/chronic' for the SMG (Z = -2.47, P = 0.013) (Table 9). A significant decrease in the median score from 3.67 to 3.00 (Z = -2.43, P = 0.015) was found in the CG in 'personal control'.

6.2.1.1.3 Causal Dimension

In the causal dimension, the results of self-report causal items and degree of causal attribution are presented. Among all self-report causal items, the highest reported item was 'don't know or never thought of' (52%) in the participants, implying that they have no idea of or they have never thought of the causes of their disease. It was followed by 'smoking' (44%) and 'pollution' (38%) (Table 10). Overwork (24%) was the fourth highest reported factor considered influential in COPD and there was a vast report of causal agents (40%) identified beyond the given 18 causal items, for instances, recurrent flu, malnutrition, cold weather, poor living condition, exposure to chemicals, and others. In addition, there was a more obvious drop in reporting 'don't know or never thought of' in the SMG at T2 (24%) from T0 (5%) than that was in CG (from 28% to 12%). The SMG also had a higher increase in reporting 'smoking' and 'environment pollution' to be causal agents at T2 from T0 than CG did. Nonetheless, 'overwork' and 'others' remained highly mentioned at the two time points.

Table 10 Self-report causal attributions for COPD

Causal agent	Percentage of patients reporting causal agent (%)				
	Total	SMG		CG	
	T0 (n=50)	T0 (*n*=26)	T2 (*n*=23)	T0 (*n*=24)	T2 (*n*=19)
Don't know or never thought of	52	24	5	28	12
Smoking	44	24	29	20	10
Pollution in the environment	38	14	24	24	20
Overwork	24	18	24	6	12
Altered immunity	20	14	15	6	12
Ageing	18	12	15	6	24
Alcohol	12	6	7	6	7
Poor medical care in my past	12	8	2	4	12
Hereditary	10	4	10	6	7
Stress or worry	10	6	5	4	0
A germ or virus	8	0	2	8	7
Diet or eating habits	6	2	2	4	5
Accident or injury	2	0	0	2	0
Family problems or worries	2	2	0	0	0
My emotional status	2	2	0	0	0
My own behaviour	0	0	5	0	0
Others	40	20	15	20	12

With regard to the degree of causal attribution (See Table 11), no attempt was made to compute comparison within groups in the causal dimension as there is a too diverse or sparse distribution in each item to perform an adequate statistical analysis. To examine the average score of overall items, the SMG was more inclined to attribute their illness to their immune status and risk factors than to psychological status and to chance/accident. Items most strongly agreed by the participants as causal attribution to COPD were ‘altered immunity’ (T0 : 3.98, T2 : 4.00), ‘environmental pollution’ (T0 : 3.57, T2 : 3.68) and ‘ageing’ (T0 : 3.70, T2 : 3.68) respectively. Wilcoxon signed ranks test was performed to compare the subscales between groups and the results showed that the participants held their illness attributive beliefs consistently in prior to and after the trial as no significant difference was found for both the SMG and CG at the two time intervals.

Table 11 Comparisons of the IPQ – causal items perceived by patients in SMG at T0 and T2.

Causal dimensions Subscale items (range 1-5)	SMG			*Z*	*P*-value
	range	T0 (*n* = 26) Median (range#)/ Mean (SD)	T2 (*n* = 23) Median (range#)/ Mean (SD)		
Psychological attributions	6 - 30	17.0 (12.0-18.5)	15.0 (11.8-18.3)	-1.20	0.23
Stress or worry		2.76 (1.29)	2.35 (1.29)		
My mental attitude		2.37 (0.97)	2.08 (1.10)		
Family problems or worries		2.29 (0.98)	2.10 (1.19)		
Overwork		3.32 (1.27)	3.23 (1.35)		
My emotional status		2.53 (1.19)	2.15 (1.12)		
My personality		2.29 (0.79)	2.05 (1.04)		
Risk factor attributions	7 - 35	21.0 (18.0-23.5)	20.0 (17.8-24.0)	-1.29	0.20
Hereditary		2.60 (1.13)	2.45 (1.38)		
Diet or eating habits		2.71 (1.00)	2.55 (1.30)		
Poor medical care in my past		3.22 (1.25)	3.00 (1.41)		
My own behaviour		3.21 (1.17)	2.98 (1.44)		
Ageing		3.70 (1.04)	3.68 (1.21)		
Alcohol		2.34 (1.14)	2.33 (1.31)		
Smoking		3.50 (1.53)	3.40 (1.60)		
Immune attributions	3 - 15	10.5 (9.0-12.0)	11.5 (10.0-12.0)	-1.03	0.30
A germ or virus		3.08 (1.04)	3.25 (1.28)		
Pollution in the environment		3.57 (1.16)	3.68 (1.07)		
Altered immunity		3.98 (0.92)	4.00 (0.78)		
Chance attributions	2 - 10	5.5 (4.0-6.0)	4.0 (3.8-6.0)	-0.26	0.80
Chance or bad luck		2.53 (1.21)	2.45 (1.30		
Accident or injury		2.12 (0.75)	1.93 (0.92)		

Interquartile range.

6.2.1.2 Self-efficacy

Table 12 shows the means and *Z* scores of the CSES by groups and overall sample in baseline analysis. For the mean scores of all samples, 'physical exertion' is the only subscale which scored below the mid-point of 3.0 (Mean 2.64, SD 0.66) and 'intense emotional arousal' had the highest score (Mean 3.30, SD 0.61). Due to skewed distribution in the measures of 'weather/environment' subgroup, Mann-Whitney U-Test was conducted to determine whether there were any significant differences between the scores for each group. There was no significant difference in all

subgroups and total score of CSES between the SMG and CG at both T0 and T2 assessments.

Wilcoxon signed ranks tests were done to identify whether there were any significant differences between T0 and T2 assessments for each group. As shown in Table 13, there were no significant differences found in all subgroups and total scores of CSES in the CG. In SMG, there was a significant increase from T0 to T2 in the total scale (Z = -2.44, P = 0.015) and three subgroups: 'intense emotional arousal' (Z = -2.54, P = 0.01), 'physical exertion' (Z = -2.57, P = 0.01) and 'weather/environment (Z = -2.63, P < 0.001).

Table 12 The scores of total CSES and its subgroups and baseline comparison of SMG and CG

Subgroup	Tier 0			*Z*	*P*-value
	All samples (n=48)	Median (range)			
	Mean (SD)	SMG (*n*=25)	CG (*n*=23)		
Negative affect	3.23 (0.63)	3.10 (2.90-3.60)	3.40 (2.60-3.90)	-0.73	0.47
Intense emotional arousal	3.30 (0.61)	3.10 (2.95-3.65)	3.40 (3.00-4.00)	-1.04	0.30
Physical exertion	2.64 (0.66)	2.80 (2.20-3.00)	2.60 (2.20-3.00)	-0.35	0.72
Weather/ Environment	3.17 (2.51)	2.80 (2.20-3.10)	3.00 (2.30-3.50)	-1.13	0.26
Behavorial risk factors	3.25 (0.76)	3.00 (3.00-3.50)	3.00 (2.50-4.00)	-0.72	0.47
Total CSES score	3.14 (0.79)	3.00 (2.70-3.35)	3.30 (2.60-3.60)	-0.86	0.39

Table 13 Comparison of mean differences in self-efficacy scores between T0 and T2

Subgroup	SMG Median(range#)		*Z*	CG Median (range#)		*Z*
	T0 (n=25)	T2 (n=23)	(*P*-value)	T0 (n= 23)	T2 (n=18)	(*P*-value)
Negative affect	3.10	3.55	-1.81	3.40	3.60	-1.60
	(2.90-3.60)	3.10-4.00)	(0.07)	(2.60-3.90)	(3.23-4.00)	(0.11)
Intense emotional	3.10	3.70	-2.54	3.40	3.75	-0.71
arousal	(2.95-3.65)	(3.10-4.10)	(0.01)*	(3.00-4.00)	(3.00-4.03)	(0.48)
Physical	2.80	3.00	-2.57	2.60	2.80	-0.83
exertion	(2.20-3.00)	(2.20-4.00)	(0.01)*	(2.20-3.00)	(2.55-3.40)	(0.41)
Weather/	2.80	3.50	-2.63	3.00	3.10	-0.36
Environment	(2.20-3.10)	(2.70-4.0)	(0.008)**	(2.30-3.50)	(2.45-3.55)	(0.72)
Behavorial	3.00	3.50	-1.18	3.00	4.00	-0.63
risk factors	(3.00-3.50)	(2.88-4.00)	(0.24)	(2.50-4.00)	(3.00-4.00)	(0.53)
Total CSES	3.00	3.50	-2.44	3.30	3.40	-1.00
score	(2.70-3.35)	(3.00-4.00)	(0.015)*	(2.60-3.60)	(2.90-3.73)	(0.32)

Interquartile range

* *P*-value <0.05; ** *P*-value < 0.01

6.2.1.3 Accuracy of Inhaler technique

The average accuracy of inhaler technique for the participants was 56.6% (SD = 21.2) in which there was no significant difference in both SMG and CG at baseline (F = 3.2, P = 0.08) (Table 14). Among all inhalers, the mastery rate of MDI was the lowest (41.7%, range 33.3-58.3), followed by MDI using together with spacer (61.9%, range 47.5-69.2), handihaler (62.5%, range 56.3-64.1), turbuhaler (64.3%, range 55.3-78.6) and accuhaler (69.2, range 65.4-80.8). In Mann-Whitney U-test, no significant differences were found at T0 with the mastery rate of MDI (U = 109.5, P = 0.71), MDI using together spacer (U=7.5, P = 0.54), Accuhaler (U = 0.5, P = 0.02) and handihaler (U = 10.0, P = 0.58) between SMG and CG. However, considering that the total number of samples using turbuhaler was less than eight (n = 6), related samples test had not performed on comparing the mastery rate of turbuhaler between groups (Plichta and Garzon, 2009).

Table 14 Mastery rate of inhaler usage and comparison of SMG and CG at T0.

Types of inhalers		Total samples Median (range#)	SMG Median (range#)	CG Median (range#)	*U*-test	*F*	*P*-value
All inhalers	% (SD)	56.7 (21.2)	55.0 (18.6)	58.6 (24.2)		3.2	0.49
MDI	(n=31)	41.7 (33.3-58.3)	50.0 (34.9-58.3)	37.5 (29.4-77.1)	109.5		0.71
MDI + Spacer	(n=9)	61.9 (47.5-69.2)	68.3 (50.8-69.6)	57.9 (47.5-70.4)	7.5		0.54
Turbuhaler	(n=6)	64.3 (55.3-78.6)					
Accuhaler	(n=10)	69.2 (65.4-80.8)	69.2 (53.8-69.2)	92.3 (76.9-100.0)	0.5		0.02*
Handihaler	(n=10)	62.5 (56.3-64.1)	62.5 (56.3-62.5)	62.5 (56.3-75.1)	10.0		0.58

Interquartile range

* *P*-value <0.05

Due to the small number of users of various inhalers, two combined groups of inhalers, namely 'all inhalers' and 'dry powder inhalers' are formed for computing comparisons between T0 and T1 and T2 (as showed in Table 15). Wilcoxon signed ranks tests showed that the mastery rates in SMG were significantly higher at T1 and T2 than T0 in terms of usage of all inhalers (T1 84.6% > T0 58.3, Z = 3.92, P = 0.000); (T2 83.3% > T0 58.3%, Z = -3.92, P = 0.000), MDI (T1 75.0% > T0 50.0, Z = -3.18, P = 0.001); (T2 83.3% > T0 50.0, Z = -3.30, P = 0.001), and dry powder inhalers (T1 87.5 > T0 62.5, Z = -2.37, P = 0.02); (T2 85.7 > T0 62.5, Z = -2.20, P = 0.03). In the comparison between T1 and T2 in SMG, no significant differences were found on groups of all inhalers, MDI and dry powder inhalers. On the other hand, there was a significant difference in the median mastery rate of all inhalers group between T0 and T2 in CG (Z = -2.20, P = 0.04), but no significant differences in MDI (Z = -1.69, P = 0.09) and dry powder inhalers (Z = -1.27, P = 0.20). In Mann-Whitney U-tests, no significant differences were found between SMG and CG at T0 in mastery rate of all inhalers, MDI and dry powder inhalers, however, the median mastery rates of all inhalers at T2 were found significantly higher for SMG than CG (83.3% > 71.4%, U = 208.0, P = 0.045).

Table 15 Comparison of mastery rate of inhalers at different time points within and between groups

Types of inhalers		Tier 0		Tier 1		Tier 2		*Z*	*P*-value
		Median	range #	Median	range #	Median	range #		
All inhalers									
SMG	(n=21) †	58.3	45.3-68.4	84.6	75.0-91.7			-3.92	0.00**
	(n=19) †			84.6	75.0-91.7	83.3	75.0-85.7	-0.11	0.91
	(n=20) †	59.3	45.3-68.5			83.3	75.0-85.7	-3.92	0.00**
CG	(n=20) †	58.1	39.6-78.7			71.4	58.3-83.3	-2.20	0.04*
U-test		491.0				208.0			
P-value		0.53 (*n* =66)				0.045* (n=50)			
MDI									
SMG	(n=14) †	50.0	34.9-58.3	75.0	65.9-85.4			-3.18	0.00**
	(n=12) †			75.0	65.9-85.4	83.3	72.9-83.3	-0.98	0.33
	(n=14) †	51.0	34.9-58.4			83.3	72.9-83.3	-3.30	0.00**
CG	(n=11) †	37.5	29.4-771			66.7	33.3-83.3	-1.69	0.09
U-test		109.5				53.5			
P-value		0.71 (*n* =31)				0.18 (*n* =25)			
Dry powder inhalers									
SMG	(n=7) †	62.5	53.8-69.2	87.5	84.6-93.8			-2.37	0.02*
	(n=7) †			87.5	84.6-93.8	85.7	78.6-92.6	-1.18	0.24
	(n=6) †	63.5	53.8-69.3			85.7	78.6-92.6	-2.20	0.03*
CG	(n=7) †	65.7	56.5-78.8			76.8	69.5-90.0	-1.27	0.20
U-test		124.0				48.5			
P-value		0.35 (*n* =35)				0.11 (*n* =25)			

Interquartile range

† refers to number of pairs for testing

* *P*-value < 0.05; *P*-value < 0.01

6.2.2 Secondary outcomes

6.2.2.1 Pulmonary function

Comparisons of the post-BD FEV_1 and post-BD FEV_1 % predicted between T0 and T2 were computed by Wilcoxon signed ranks test and results were showed in Table 16. There was significant increase in the post-BD FEV_1 in both SMG (Z = -2.27, P = 0.023) and CG (Z = -2.22, P = 0.027) between the two time points while no significant differences were found in the post-BD FEV_1 % predicted accordingly. On condition that the measures of post-BD FEV_1 and post-BD FEV_1 % predicted were normally distributed and the total sample size was 42 at T2, independent t-tests were conducted to compare the two groups at T2 and there was no significant difference in the means of SMG and CG (See Table 17).

Table 16 Comparison of pulmonary functions between T0 and T2 for SMG and CG .

	SMG (n = 23†) Median (range#)		Z (P-value)	CG (n = 19†) Median (range#)		Z (P-value)
	Tier 0	Tier 2		Tier 0	Tier 2	
Post-BD FEV_1	0.99 (0.70-1.51)	1.12 (0.76-1.60)	-2.27 (0.023)*	1.01 (0.61-1.54)	1.03 (0.87-1.58)	-2.22 (0.027)*
Post-BD FEV_1 % predicted	48.0 (38.3-64.5)	49.0 (40.0-69.0)	-0.86 (0.39)	46.0 (32.3-57.8)	47.5 (38.0-68.0)	-1.87 (0.06)

Interquartile range

* P-value <0.05

† refers to number of pairs for testing

Table 17 Comparison of pulmonary functions between SMG and CG at T2.

	SMG (n = 26)		CG (n = 24)		F	P-value
	Mean	SD	Mean	SD		
Post-BD FEV_1	1.19	0.49	1.23	0.54	0.02	0.81
Post-BD FEV_1% predicted	52.8	22.1	54.1	21.0	0.00	0.85

6.2.2.2 Rescue medication and Healthcare utilization

Wilcoxon signed ranks tests were conducted to compare the median of the above variables between T0 and T2 for the SMG and CG. As shown in Table 18, the participants of both groups adopted similar frequency in using the rescue medication and in paying visit to the MD and ER at T0 and T2. However, the SMG had less days of hospitalization at T2 than at T0 while the CG remained unchanged and this difference was statistically significant (T2 0.0 < T0 2.0, Z = -2.24, P = 0.025). In regard to the comparison between groups at T2, the Mann-Whitney U-test did not show any significant difference in the three variables (See Table 19).

Table 18 Comparison of rescue medication and health care utilization at T0 and T2 between SMG and CG

	SMG (*n* = 23†) Median (range#)		*Z* (*P*-value)	CG (*n* = 19†) Median (range#)		*Z* (*P*-value)
	Tier 0	Tier 2		Tier 0	Tier 2	
Frequency of using SABD	0.0 (0.0-4.0)	1.0 (0.0-2.0)	-0.16 (0.88)	0.0 (0.0-2.8)	1.0 (0.0-2.0)	-0.72 (0.47)
Never use *f* (%)	14 (53.8)	11 (47.8)		14 (58.3)	8 (42.1)	
1-2 times/week	2 (7.7)	2 (8.7)		2 (8.3)	2 (10.5)	
2-7 times/week	3 (11.5)	5 (21.7)		2 (8.3)	5 (26.3)	
Once per day	0 (0.0)	0 (0.0)		2 (8.3)	0 (0.0)	
> once per day	7 (26.9)	5 (21.7)		4 (16.7)	4 (21.1)	
No. of unplanned visit to MD or ER	1.5 (0.0-4.0)	0.0 (0.0-2.0)	-1.17 (0.24)	1.0 (0.0-3.5)	1.0 (0.0-3.0)	-0.68 (0.50)
Days of hospitalized	2.0 (0.0-10.3)	0.0 (0.0-0.0)	-2.24 (0.025)*	0.0 (0.0-8.0)	0.0 (0.0-0.0)	-0.66 (0.51)

Interquartile range

* *P*-value <0.05

† refers to number of pairs for testing.

Table 19 Comparison of medical utilization in past 6 months between SMG and CG at T2.

	SMG (*n* = 23)		CG (*n* = 19)		*U*-test	*P*-value
	Median	Range#	Median	Range#		
Frequency of using short-acting bronchodilator	1.0	0.0-1.0	1.0	0.0-2.0	209.5	0.81
No. of unplanned visit to out-patient or Emergency room	0.0	0.0-2.0	1.0	0.0-3.0	179.5	0.29
Days of hospital admission	0.0	0.0-0.0	0.0	0.0-0.0	192.5	0.28

Interquartile range

6.2.2.3 Generic health-related quality of life

The mean SF-36 scores of all participants were shown in table 20. In general, their mean score for mental health summary (50.1, SD=9.1) was higher than that of physical health summary (39.6, SD=8.9). Among all subgroups, the mean bodily pain score was the highest (50.0, SD=12.8), followed by mental health (49.1, SD=8.6), vitality (48.6, SD-=12.1), role-emotional (45.8, SD=10.0), social

functioning (45.3, SD=12.7), role-physical (42.9, SD=10.3), physical functioning (40.3, SD=11.0), general health (32.2, SD=10.1). Provided that the 'bodily pain' measures were not normally distributed, Mann-Whitney U-test was done to compare the median of each SF-36 subgroups between SMG and CG at T0 and T2, however, no significant difference was identified in the *U*-statistics at both time points.

Table 20 The scores of SF-36 and baseline comparison of SMG and CG

Subgroup	Total Mean (SD) T0 (*n*=50)	T0 Median (range#) SMG (*n*=26)	CG (*n*=24)	*U*-test	*P*-value
Physical Functioning	40.3 (11.0)	41.3 (31.8-50.7)	40.2 (28.6-52.3)	305.0	0.89
Role-Physical	42.9 (10.3)	43.4 (32.4-52.6)	44.6 (37.3-52.0)	260.0	0.43
Bodily pain	50.0 (12.8)	48.4 (37.2-62.1)	62.1 (37.6-62.1)	272.0	0.57
General Health	32.2 (10.1)	31.5 (23.4-38.2)	28.2 (23.4-41.6)	264.5	0.82
Vitality	48.6 (12.1)	47.4 (39.6-56.0)	49.0 (45.9-55.2)	265.5	0.50
Social Functioning	45.3 (12.7)	45.9 (37.8-55.9)	51.4 (35.0-56.9)	257.0	0.51
Role-Emotional	45.8 (10.0)	44.2 (36.4-55.9)	48.1 (44.2-55.9)	236.0	0.20
Mental Health	49.1 (8.6)	47.2 (43.0-54.2)	50.0 (44.4-55.6)	221.5	0.17
Perception					
Physical health summary	39.6 (8.9)	39.9 (33.9-47.1)	40.7 (32.0-46.7)	263.0	0.80
Mental health summary	50.1 (9.1)	49.9 (42.7-55.2)	53.5 (46.4-60.6)	209.0	0.16

Interquartile range

In Table 21, the Wilcoxon signed ranks tests revealed that there was no significant difference in the median of each SF-36 subgroup between T0 and T2 for both SMG and CG. Among all subgroups, the participants of both groups scored their general health the lowest (median 26.7 – 35.3) throughout the two time points and they were much lower than the Hong Kong norm of 55.98 (95% CI : 55.17 – 56.78) (Lam, 1999).

Table 21 Comparison of medians in SF-36 between T0 and T2

Subgroup	SMG Median (range#) (*n* = 23†)		*Z* (*P*-value)	CG Median (range#) (n = 18†)		*Z* (*P*-value)
	Tier 0	Tier 2		Tier 0	Tier 2	
Physical Functioning	41.30 (31.8-50.7)	36.0 (27.6-50.7)	-0.99 (0.32)	40.20 (28.6-52.3)	38.1 (29.7-52.8)	-0.33 (0.74)
Role-Physical	43.40 (32.4-52.6)	42.2 (29.9-54.4)	-0.174 (0.86)	44.60 (37.3-52.0)	45.8 (33.6-54.4)	-0.88 (0.38)
Bodily pain	48.40 (37.2-62.1)	50.3 (33.0-62.1)	-0.63 (0.53)	62.10 (37.6-62.1)	52.8 (41.4-62.1)	-0.04 (0.97)
General Health	31.50 (23.4-38.2)	26.7 (25.8-44.8)	-0.27 (0.78)	28.20 (23.4-41.6)	35.3 (25.4-44.4)	-1.14 (0.26)
Vitality	47.40 (39.6-56.0)	52.1 (45.9-58.3)	-1.33 (0.184)	49.00 (45.9-55.2)	50.5 (39.6-64.6)	-0.45 (0.65)
Social Functioning	45.90 (37.8-55.9)	51.4 (35.0-56.9)	-0.27 (0.79)	51.40 (35.0-56.9)	56.9 (40.5-56.9)	-0.91 (0.37)
Role-Emotional	44.20 (36.4-55.9)	52.0 (32.6-55.9)	-0.50 (0.62)	48.10 (44.2-55.9)	50.0 (39.4-55.9)	-0.57 (0.57)
Mental Health Perception	47.20 (43.0-54.2)	52.8 (44.4-58.5)	-1.27 (0.21)	50.00 (44.4-55.6)	58.5 (44.4-61.3)	-1.06 (0.29)
Physical health summary	39.9 (33.9-47.1)	38.60 (31.4-45.1)	-0.79 (0.43)	40.7 (32.0-46.7)	39.7 (34.0-47.7)	-0.213 (0.83)
Mental health summary	49.9 (42.7-55.2)	52.60 (42.0-59.5)	-1.065 (0.29)	53.5 (46.4-60.6)	54.2 (49.3-60.0)	-0.024 (0.98)

Interquartile range

† refers to number of pairs for testing.

6.2.2.4 Disease-Specific health-related quality of life

The results of SGRQ are presented in regard to the overall and subgroup scores of SGRQ, and scores comparison between groups and within groups. In Table 22, there were the scores for total SGRQ and its three subgroups. The participants scored most poorly in the 'activity score' with a mean score of 55.1 (SD = 24.1) and the best in 'impact score' with a mean score of 43.1 (SD = 16.9). In the baseline comparison, independent samples t-test did not show any significant differences in the mean scores of the 'total' (F = 1.13, P = 0.29), 'symptom' (F = 1.17, P = 0.29), 'activity'

(F = 0.05, P = 0.83) and 'impact' (F = 0.12, P = 0.73) subgroups of SGRQ between the SMG and CG at T0, and so did not at T2.

Table 22 The scores of total SGRQ and its subgroups and baseline comparison of SMG and CG

Subgroup	All samples	T0 Mean(SD)[δ]		*F*	*P*-value
	T0 (n=50)	SMG (*n*=25)	CG (*n*=23)		
Symptom score	47.9 (24.5)	48.1 (25.9)	47.6 (23.5)	1.17	0.95
Activity score	55.1 (24.1)	54.2 (24.8)	56.1 (23.7)	0.05	0.77
Impact score	43.1 (16.9)	44.5 (17.1)	41.6 (16.9)	0.12	0.55
Total score	47.8 (16.1)	48.0 (17.7)	47.5 (14.5)	1.13	0.92

[δ] Higher score indicates worse quality of life.

Table 23 Comparison of SGRQ scores between T0 and T2

Subgroup	SMG Median (range*)[δ] (*n* = 23†)		*Z* (*P*-value)	CG Median (range*)[δ] (n=18†)		*Z* (*P*-value)
	T0	T2		T0	T2	
Symptom score	46.5 (24.7-70.0)	32.6 (8.9-51.9)	-2.04 (0.042)*	50.7 (26.6-66.9)	39.6 (33.7-65.9)	0.00 (1.00)
Activity score	48.5 (38.2-79.4)	59.5 (35.1-80.3)	-0.94 (0.35)	48.1 (38.3-77.6)	47.5 (35.3-66.4)	-1.01 (0.31)
Impact score	47.4 (31.9-57.3)	38.0 (22.7-58.2)	-0.34 (0.74)	39.1 (28.1-52.6)	34.2 (17.2-48.6)	-0.54 (0.59)
Total score	47.0 (31.4-61.3)	47.1 (27.1-60.5)	-0.61 (0.54)	47.9 (36.4-55.6)	42.9 (28.0-58.6)	-0.33 (0.74)

Interquartile range

* *P*-value <0.05

† refers to number of pairs for testing.

[δ] Higher score indicates worse quality of life.

In Table 23, Wilcoxon signed ranks test revealed marginally significant decrease in the median in the 'symptom score' (Z = -2.04, P = 0.042) for the SMG across the two time intervals between T0 and T2 while that of the CG remained unchanged.

6.3 Part Three Bivariate correlations for Self-efficacy and Illness representations

In this section, the results of Pearson's product moment correlation coefficient of the subscales of CSES and illness representations that explored the relationship between self-efficacy and illness perception beliefs in COPD patients are presented (as showed in Table 24). All variables, except 'timeline acute/chronic' of illness representations were found to be significantly correlated to one or more subscales of CSES. 'Identity' of illness representations was negatively correlated with 'negative effect', 'intense emotional arousal' and 'total score' of CSES. This relationship indicates that patients with more perceived symptoms were more likely to feel less confidence in managing difficulty in breathing at times of exacerbation and stressful condition and intense emotions. 'Consequences' and 'timeline cyclical' of the illness representations were positively and very significantly correlated with 'negative effect' and 'total CSES', and negatively and very significantly correlated to 'intense emotional arousal' and 'behavorial risk factors', additionally, 'consequence' is also negatively and significantly correlated with 'physical exertion'. 'Personal control' was only positively and significantly correlated with 'physical exertion', indicating that the better personal control the patients perceived for themselves, the more likely they feel confident in managing difficulty of breathing when they exercise, climb up stairs, etc. For 'treatment control' of illness representations, it was positively and significantly correlated with 'negative effect', 'intense emotional arousal', 'physical exertion' and 'total score' of CSES. 'Illness coherence' was positively and significantly correlated with all CSES subgroups except for 'physical exertion'. 'Emotional representations' was negatively and significantly correlated with 'negative effect', 'intense emotional arousal', 'behavorial factors' and 'total score' of CSES. This indicates that patients with worse perceived negative emotion were more likely to feel less confident in managing difficulty of breathing during exacerbation, anger and fear, and improper diet.

Table 24 Correlation between self-efficacy and illness representations.

Predictors	Negative effect	Intense emotional arousal	Physical exertion	Weather/ Environment	Behavorial risk factors	Total CSES
Identity	-0.397*	-0.350*	-0.231	-0.244	-0.237	-0.360*
Timeline	-0.113	-0.176	-0.144	-0.090	-0.077	-0.142
Consequences	-0.440**	-0.461**	0.355*	-0.270	-0.367*	-0.445**
Personal control	0.206	0.232	0.360*	0.256	0.233	0.289
Treatment control	0.332*	0.318*	0.383*	0.232	0.256	0.350*
Illness coherence	0.329*	0.336*	0.221	0.323*	0.339*	0.339*
Timeline cyclical	-0.491**	-0.522**	-0.310	-0.385*	-0.503**	-0.503**
Emotional representations	-0.354*	-0.386*	-0.290	-0.192	-0.376*	-0.376*

*P-value < 0.05; **P –value < 0.01

6.4 Part Four Factors affecting illness perception, self-efficacy and HRQoL of COPD patients

In Table 25, Pearson's product moment correlation coefficient was conducted on demographic and clinical variables to identify their potential association with the illness perception, self-efficacy and the generic and disease-specific health related quality of life of COPD patients. The table does not show all subscales of these measures, rather variables were selected according to two criteria: 1) significant changes indicated after the intervention; 2) association indicated in more than one demographic and clinical variables. Among all dimensions of illness representations, 'consequences' was indicated to be associated with most variables, including 'stage of disease' (rho = 0.56, df = 38, P <0.01), 'post-BD FEV1% predicted' (r = -0.58, df = 38, P <0.01), 'long-term treatment' (rho = 0.35, df = 38, P = 0.026), 'prescribed MDI' (rho = 0.40, df = 38, P <0.01) and 'frequency of using SABA' (rho = 0.52, df = 38, P <0.01). This association indicates that patients with a perception of serious consequences with their disease were more likely to be in a severe stage of their disease, to have a poorer pulmonary function, to have been prescribed MDI and to be frequently using SABA. In the meantime, 'timeline cyclical' was also positively and significantly correlated with 'prescribed MDI' and 'frequency of using SABA' while 'timeline acute/chronic' only has a positive and significant correlation with 'long-term treatment'. The 'total CSES' was significantly correlated with 'stage of disease' (rho = -0.58, df = 38, P <0.01), 'post-BD FEV1% predicted' (rho = 0.57, df = 38, P <0.01) and 'long-term treatment' (rho = -0.34, df = 38, P = 0.035). The total SGRQ was found to be negatively and very significantly correlated with total and all subgroups of CSES (r = -0.41 to -0.53, df = 38 - 39, P <0.01) in additional to statistically positive association with 'stage of disease' (rho = 0.57, df = 40, P <0.01), 'post-BD FEV1% predicted' (r = -0.58, df = 40, P <0.01), 'prescribed MDI' (rho = 0.32, df = 40, P = 0.038) and 'frequency of using SABA' (rho = 0.57, df = 40, P <0.01). In regard to SF-36, its physical health summary demonstrated significant correlation with 'stage of disease' (rho = -0.47, df = 39, P <0.01) , 'post-BD FEV1% predicted' (r = 0.47, df = 39, P <0.01),

'prescribed MDI' (rho = -0.39, *df* = 39, *P* = 0.012), 'frequency of using SABA' (rho = -0.56, *df* = 39, *P* <0.01) and 'negative effect' (*r* = 0.36, *df* = 38, *P* <0.021), 'intense emotional arousal' (*r* = 0.34, *df* = 38, *P* <0.034) and 'total scores of CSES' (*r* = 0.31, *df* = 38, *P* = 0.048). Mental health summary did not show any significant association with any demographic, clinical variables and 'behavioral risk factors' of CSES, but showed significant correlation with all other subgroups (*r* = 0.33 to 0.41, *df* = 38 - 39, *P* = 0.035 – 0.008) and total score of CSES (*r* = 0.41, *df* = 38, *P* < 0.01).

Table 25 Correlation between demographic variables and IPQ subscales, total CSES, total and symptom score of SGRQ and PCS and MCS of SF-36

	Illness representations			Total	SGRQ		SF-36	
Variables	Timeline	Consequences	Timeline cyclical	CSES	Total SGRQ	Symptom Score	Physical health summary	Mental health summary
Age	0.16	0.01	-0.30	0.21	-0.04	-0.02	-0.14	0.27
Sex	0.14[a]	0.15[a]	0.17[a]	-0.06[a]	-0.08[a]	-0.26[a]	-0.09[a]	0.10[a]
Years of diagnosis	-0.16[a]	0.08[a]	-0.19[a]	-0.23[a]	0.18[a]	0.17[a]	-0.14[a]	0.05[a]
Stage of disease	0.30[a]	0.56[a] **	0.24[a]	-0.58[a] **	0.57[a] **	0.08[a]	-0.47[a] **	-0.20[a]
Post-BD FEV1 % Pred.	-0.20	-0.58**	-0.22	0.57**	-0.59**	-0.11	0.47**	0.20
Concomitant disease	0.16	0.10	0.07	-0.16	0.11	0.06	-0.17	-0.15
Smoke pack year(s)	-0.10[a]	0.04[a]	-0.07[a]	0.07[a]	0.18[a]	0.36[a] *	-0.05[a]	0.01[a]
Secondary or above level of education	--	--	--	-0.04[a]	-0.09[a]	-0.08[a]	-0.01[a]	-0.10[a]
Living with family	--	--	--	0.18[a]	-0.08[a]	0.13[a]	-0.01[a]	0.13[a]
Married	--	--	--	0.28[a]	-0.11[a]	0.23[a]	0.02[a]	-0.12[a]
Self-paid of medical expenses	--	--	--	--	--	--	0.23	-0.22
Long-term treatment	0.36[a] *	0.35[a] *	0.17[a]	-0.34[a] *	0.27[a]	0.06[a]	-0.27[a]	-0.13[a]
Prescribed MDI	0.26[a]	0.40[a] *	0.42[a] **	-0.14[a]	0.32[a] *	0.19[a]	-0.39[a] *	-0.09[a]
Frequency of using SABA	0.13[a]	0.52[a] **	0.32[a] *	-0.23[a]	0.57[a] **	0.33[a] *	-0.56[a] **	0.05[a]
Mastery rate of all inhalers	--	--	--	0.17[a]	-0.07[a]	-0.09[a]	0.20[a]	0.03[a]
CSES								
Negative effect	--	--	--	--	-0.53**	0.00	0.36 *	0.40 *
Intense emotional arousal	--	--	--	--	-0.52**	0.07	0.34 *	0.33 *
Physical exertion	--	--	--	--	-0.46**	0.01	0.22	0.36*
Weather/Environment	--	--	--	--	-0.50**	-0.09	0.21	0.41**
Behavorial risk factors	--	--	--	--	-0.41**	0.10	0.23	0.31
Total CSES score	--	--	--	--	-0.56**	0.01	0.31	0.41**

*P-value < 0.05; **P –value < 0.01; [a] Spearman's rank-order correlation coefficient (rho)

6.5 Summary

This chapter has reported the baseline characteristic of the sample and the findings in relation to the assessment of the effects of SMEP on COPD patients in Macau. Firstly, the SMG and CG were found relatively homogenous in terms of their demographic and clinical characteristics. Significant differences were comparatively identified more within groups in time than between groups in all measurements. To compare difference between groups, significant difference was indicated only in mastery rate of all inhalers at T2. On the other hand, significant differences were indicated for SMG between T0 and T2 in primary outcomes for instances, 'timeline acute/chronic' subgroup of IPQ-R, 'intense emotional arousal', 'physical exertion', 'weather/environment' subgroups and total score of CSES, mastery rate of all inhalers, MDI and dry powder inhalers; and in secondary outcomes for instances, post-BD FEV_1 for SMG and CG, days of hospitalization, and symptom score of SGRQ. The result also revealed that the participants were more inclined to attribute COPD to their immune status and risk factors. In the bivariate correlations for self-efficacy and illness perception, all subgroups excluding 'timeline acute/chronic' of illness representations indicated significant correlation with one or more subscales of CSES. In identifying factors of affecting illness perception, self-efficacy and HRQOL of COPD patients, participant characteristics including stage of disease, pulmonary function variable, amount of smoking, long-term treatment, prescribed MDI and frequency of using SABA in varying degree correlated significantly with subgroups of illness representations, total CSES, 'symptom' and total score of SGRQ and physical health summary of SF-36. In addition, CSES subgroups significantly correlated to total SGRQ and mental health summary of SF-36. With these findings in place in the mixed methods design, qualitative data was concurrently collected to explore the subjective perspectives of the participants towards self-management. The next chapter will present the qualitative findings in terms of the analysis and interpretation of the focus groups.

Chapter Seven Qualitative Findings

7.1 Introduction

Based on thematic analysis from three focus groups, the qualitative findings were obtained in relation to the research question which explored the perceptions and experiences of COPD patients towards self-management in Macau. In these focus groups, two features in relation to the oral expression of the participants were identified. First, they did not express their ideas in well-structured speeches although they talked with their mother tongue – Cantonese. This may be due to their low education level. Therefore, the transcript of the focus groups which was translated from Cantonese to English with an intention to keep the original tone of the participants may be presented in irrelevant wordings or incomplete sentences. Second, the responses of the participants indicated that they did not distinguish between the concepts of perception and experiences. They simply mixed these two concepts up when sharing and commenting on self-management. Therefore, no distinct differentiation of these concepts was made throughout the thematic development process and the themes that did emerge reflect a unified meaning for both the perception and experience of self-management in Macau COPD patients. It should be noted that the term, SMEP, was regularly referred to as 'workshop' or 'the education' or 'the programme' by the participants in the focus group dialogue. The major theme that emerged from the focus groups was 'Essentiality'. Under this overarching core theme, five sub-themes emerged: (1) helplessness, (2) mutual involvement, (3) control, (4) support and (5) beneficial. The categorical components of these themes are summarized in table 26.

In this chapter, the findings related to this core theme and its associated sub-themes will be presented with quotations elicited largely in the forms of interactions and partially in significant individual dialogue. These findings are presented in an interpretative form of integrating the results and discussion of the focus groups. I will firstly address the main theme, 'Essentiality', in association with the five sub-themes and how they emerged from COPD patients' experiences and perceptions of self-management. Then, the relationship of the theme and all these sub-themes will be illustrated with a diagrammatic framework.

Table 26 Main theme and sub-themes that emerged from Perception and Experience of Macau COPD patients towards Self-management

Essentiality	
Helplessness • Miserable • Futile • Urgency • Negligence	Mutual Involvement • Individual obligation • Systematic level • Macro-level
Support • Emotional support • Knowledge input • Skills building • Treatment support	Control • Internalization • Agency • Incapability • Interference
Beneficial • Bodily improvement • Functional improvement • Spiritual comfort • Individual difference	

Table 27 Pseudonyms and demographic characteristics of participants in focus groups

Focus Group	Name	Age / Sex	COPD Staging	Education Level
1	Nick	61 / M	IV	Secondary
	Amy	57 / F	II	Primary
	Wilson	73/ M	II	Primary
	Ivan	73 / M	III	Primary
2	Lavin	63 / M	III	Primary
	Leon	64 / M	III	Primary
	Chris	61 / M	III	Primary
	Karen	65 / F	III	Primary
3	Winnie	47 / F	II	Primary
	Mr. Lee	63 / M	IV	Secondary
	Mrs. Lee	62 / M	III	Primary

Before exploring details of these themes, it is useful at the outset, to gain familiarity to some initials and symbols used throughout this chapter. To respect confidentiality, participants are given pseudonyms (See Table 27) and the moderator is given the initial “SL” and the workshop facilitator “Nurse MN”. In order to differentiate the only couple in the study from other individual participants, the couple are given a family name, whilst others are called by their given names. Transcript symbols are

listed and explained in Appendix 17. Quotations from two different focus groups or participants spoken at different times would be separate with '***'.

7.2 Essentiality

Essentiality, emerged as a main theme from the sub-themes following the process of analysis and comparison. The main concepts of the sub-themes were captured as: helplessness, mutual involvement, support, control and beneficial, and they elicit unified characteristics for the development of a more abstract theme. Essentiality refers to a thing that is absolutely necessary (Oxford, 2013); it implies here that self-management was something seen to be absolutely necessary by Macau COPD patients. The emergence of essentiality was prominently identified from two streams of information. First, it was explicitly expressed by the participants across the focus groups. Second, essentiality emerged as a construct transmitting the core message from the five sub-themes which demonstrated the meanings of self-management to the participants. These will be addressed and discussed in each of the sub-themes in the following. The term, essentiality, was not directly mentioned during the focus groups, participants in all focus groups generally described SMEP as important, necessary or better than nothing. This is evident when participants of all three focus groups spoke about their ignorance of COPD as indicated below:

> Karen: But it's better than not learning anything; in the past, I was like refusing to attend the workshop even though Nurse MN asked me to join several times. [B543,653,22]

***

SL: Is it necessary to have such a kind of workshop, what do you think?

Mrs. Lee At least we knew a bit..

[Winnie: That's true]

[Mr. Lee That means, at least more basic knowledge to manage myself]

Winnie: It's right, want to learn more…more. [C791, GD]

***

Wilson: For now, the workshop teaches you how and how…..Well, although you don't …don't get all, to some extent, you know what it is about. Well, you act in accordance with it, then you become better in health.

[SL Um, understood]

Wilson: …If you don't know, you are so ignorant that you don't know what to do and which is good. Since there is a workshop, you can learn what is good and then follow it…..haha!

SL: Got it…It means you know the skills through the workshop, maybe couldn't learn them all, but learnt as much as possible, right?

Wilson: Exactly.. [A941,1067,14]

To be essential, SMEP is required to be vital to the COPD patients; and it was vital because SMEP was simply basic for any person who has this chronic condition and it provided irreplaceable good to these patients. In the first and second excerpts, participants expressed SMEP as a basic element for COPD patients. In the third excerpt, Wilson pointed out the importance of SMEP when encountering their disease. However, I am also aware that the participants did not directly claim to have engaged in self-management or how important or vital self-management was to them. They mainly referred to self-management in relation to the skills they learned from the workshop and how they derived benefit from it. They tended to uphold indirectly the essentiality of self-management through praising the importance of the SMEP. This may be due to their unfamiliarity with the term 'self-management'. This is most likely to be because 'self-management' is not a popular term used among the Chinese population or in Chinese patients. In Chinese culture, patients are often in a more passive role when dealing with an illness. I say this because when Chinese patients say 'going to see doctor', they say '求醫'(qiúyī) which means asking or begging for treatment. This indicates their intrinsic passive status in carrying out their role as a patient. Self-management, in this case, has placed them into an active role which

they may be hesitant to take on. Although they did not verbally admit that they had adopted self-management or self-management was essential to them, they did implicitly by mentioning relevant meaning in the sub-themes. They expressed their inadequacy and need for SMEP in the 'helplessness' sub-theme; they anticipated for it in 'mutual involvement'; they internalized it in 'control'; they were supported by it in 'support'; and they found it beneficial in 'beneficial'. In the following section, the five sub-themes and the interrelationship that emerged between them and with the core theme in the focus groups will be delineated.

7.2.1 Helplessness

In each group session, participants consistently made a number of claims associated with three characteristics. These were grouped into three categories: miserable, futility and urgency. Helplessness was emerged among the participants who expressed the urgency for self-management after experiencing the misery of the disease and the futility of their coping. More importantly, they transferred the impact of the disease on themselves to COPD patients at large. The issue of miserable was expressed in two ways, with attention placed on how COPD greatly affects their general well-being and how the disease has a miserable impact on Macau society generally. One participant, Nick illustrated how severe he found his disease condition and this point was further echoed by another participant, Ivan.

7.2.1.1 Miserable

Nick: My disease is so severe that I sometimes really cannot reach things put high up

[Ivan: Can't use any force]

Nick: …Can't use any force, I have never been able to carry anything. Sometimes when I went shopping in the supermarket, very close to my home, I got some tissue paper there, I had difficulty in breathing when I carried my things and got myself into the lift.

SL: I see, I see, then about that…

Nick: Sometimes, it didn't work even though I put <u>great effort</u> into it! [A954-962,GD]

***

Ivan: I feel that he (Nick) became so serious, not being able even to carry something, that's really suffering.

SL: Um Um..

Nick: Yeah….I'm younger than him (Ivan) I am not that old, he (Ivan) is 10 years older than me, older than me for 10 years, the condition is still very good even older than me for 10 years, can tell by how he talks, his complexion

[Wilson: haha]

Nick: …My complexion is not good, it shows…not quite enough oxygen. [A1155,1318,GD]

The issue of negative impact of the disease was expressed across all the three focus groups. Howard et al.'s (2009) study also revealed that the majority of COPD patients expressed a moderately severe to a very severe impact on their lives. In another qualitative study on COPD patients, symptoms were interpreted as intruders as they interfere with the activities informants wanted to perform (Leidy and Haase, 1996). However, participants in this study did not show such a perspective. They had neither expressed symptoms in a third person form nor described them as an external influence, whereas symptoms were more likely to be viewed as an internal impact, for instance, 'I have never been able to carry anything', was expressed rather than 'they (symptoms) made me…..'. This may imply that they did not see their disease with 'resentment' as the participants did in Leidy and Hasse's study (1996). They may have accepted the disease as part of themselves.

Moreover, Nick illustrated the impact with several scenarios highlighting 'very close to my home' 'it didn't work even though I put great effort into it!' and his utterance was echoed by Ivan. They demonstrated a consensus by revealing how miserable they were when living under the impact of COPD. Miserable is indeed a collective

construct reflecting the symptom disturbance, physical disability, social role impairment and dreadful feeling the participants suffered from the illness and emerged throughout the focus groups. In addition, Lavin believed that this impact was not merely in the group, but existed in the majority of COPD patients. He even felt miserable for other COPD patients as he said:

> Lavin: The symptoms of these diseases, I believe there are many patients, 90% of them having the same phenomenon
>
> [Chris: must do it this way, it's weird! We can have consensus at this point]
>
> Lavin: …because they actually can't control the breathing, some lung functions is gone, right! [B21-25, GD]

Participants further mentioned that Macau society was facing the prevalence of COPD and they believed that the problem would get worse and more people suffer ignorantly from it in time.

> Nick: There are so many COPD patients nowadays..so many, when I was in the park I saw that all the elderly there were suffering from this disease, some of them didn't know their trachea is not alright, the lung is not alright, that's the situation. In fact, nowadays there are so many diseases, as well as COPD yeah, yeah, yeah quite a lot…now I think… [A802,908,8]

The same perspective was also discussed in another focus group (Refer to the second dialogue in 7.2.1.3 Urgency) and additionally they said:

> Chris: Macau is a small place
>
> [Lavin: with poor quality of air]
>
> [Karen: Yeah, yeah]
>
> Chris: …this problem will become serious later on.
>
> [Lavin &Leon : um um..] [B1583,1849,GD]

7.2.1.2 Futile

In the sub-theme category 'futile', participants had tried various avenues to manage the disease before being assigned to the self-management education programme. However, they found most avenues that they had applied were either useless or ineffective coping measures.

> Lavin: If I have not met Nurse MN before, then I exacerbated frequently, then after frequent exacerbation, well…my neighbourhood is all elderly, so something like massaging the back, sometimes massaging with ginger
>
> [SL: Massaging the back with ginger?]
>
> Lavin: …tried something like this to relax myself physically, but it's not really helpful in terms for the condition of shortness of breath
>
> [Karen: For a time…temporary maybe fine]
>
> Lavin: …Then, there were only those, the elderly…suggested me to go to…to try or to go to the balcony, was not that polluted, or to turn on the fan for a bit, something like this. [B284,347,7]

Apart from standardized medical treatment, participants also employed some folk avenues of care. These were usually shared amongst their peers and usually involved applying complementary therapies to seek a cure or remission. This is in line with the findings of self-management strategies employed by Taiwanese COPD patients who behave in similar ways (Chen et al., 2008a). In this study, participants even shared traditional or folk recipes with each other during and after the focus groups and some participants showed great interest in this form of intervention. Whether these traditional 'folk' remedies worked or not, they were neither scientifically based nor an official prescription. Thus, they can be regarded as a form of futile coping. Apart from peer advice, a participant also sought inappropriate medical measures, once again this was found to be futile.

> Nick: I was working and fairly busy that time, went usually for injection, injection is for emergency case, means an one-off medication, intravenous injection, then ended up receiving the intravenous injection every 2 days, worsening the situation. [A114,127,8]

7.2.1.3 Urgency

Participants in two focus groups proposed that it was urgent for self-management to be introduced in wider sense to the COPD population in Macau.

SL: Then is this workshop is really what you guys needed?=

Nick: =It is needed, needed, at least, there is quite a lot of knowledge that we need to know, not everyone understands this disease

[Leon: Yes, yes]

Nick: …at least one should understand some of the skills: how to control the nutrition, how to manage during exacerbation and emergency situation, have some knowledge about this.

[Leon: It means…it means the nurses.…it means there is someone to introduce us to how to understand the illness condition, and how to adapt oneself to the disease, that would be quite good]

Nick: At least I've got a basic concept about this, you know we know nothing about medicine. [A1258-1267,GD]

***

Lavin: I also hope that you guys can go on, because there are still some patients not yet…not yet known.

Karen: To search for more new patients to come here…hehe..

Chris: It is true, this one is true.

Lavin: Maybe many don't know, just don't know.

[Leon: Recently in the park I saw, a lot of men in middle age, old men and old women]

Lavin: …if some people know this…learn a bit, it would definitely be helpful.

SL: Leon has just said able to, well…er.how..in the name of us..there could be a lot of needs for this in our community.

Leon: Aye…there are many.

SL: Maybe really don't know

Lavin: Don't know

Leon: I saw some of them, really need a gimp stick to assist themselves to get up.

Chris: Let's think of one sentence I just said before, you would know it's worthwhile, can't you feel it? I really thought I was finished before the workshop, now I'm changed to another person after the workshop, now this…is the best part of our conversation! You…you…as the leading group, jot this point down immediately. I mean, there are still lots of people who don't know it, you have to contact them, to draw them into this, with a Buddha's heart, there are really so many people who can't do this. [B1556-1587,GD]

Intriguingly, Chris mentioned in the last extract that self-management education programme as such was expected to be a Buddhist act working with an altruistic heart. Two potentially different meanings could be drawn from this statement. First, SMEP is so incredibly helpful as to compare with a benevolent, a Buddhist action. Second, Chris perceived SMEP as something which is 'donated' and cannot simply be asked for. I would argue in favour of the latter understanding because the previous lines of his statement, "You…you…you as the leading group, jot this point down immediately..." expressed that the patient presumed the implementation of SMEP to be controlled or influenced by a 'leading group'. 'Leading' usually means most important while its noun form 'leaders' means the person who leads or commands a group, organization, or country. I believe with reason that SMEP was not perceived as a causal service but was something influenced by the decision of higher power. This reveals a sense of tension between the urgency of COPD SMEP and the supply of it in reality.

7.2.1.4 Negligence

Negligence was identified as one factor influencing the tension between the urgency of COPD self-management and its actual implementation. This is because the participants offered comments that they have no access to knowing about the concept of self-management and the availability of SMEP.

Lavin :Really very suffering, because you didn't know who to ask if there were any enquiry, to learn how to breath. [B417,510,7]

***

Leon :Not that usual, really!..... Not usual, really! Really, in this 20 something years of my life, I am, really….. [B1555,1817,12]

In Lavin and Leon's expressions, they showed that they did not have a notion about COPD self-management in prior to participating in this study. Leon even said that he had never heard or learned about it in the last two decades and he thought that it was not a common practice in society. This revealed either a lack of education provision or poor promotion of relevant service to COPD patients in Macau, resulting in a neglect of the needs of Macau COPD patients. Due to no relevant publication about COPD nursing care available, negligence could probably be caused by the absence of COPD education provision. Disler et al. (2012), however, addressed the impact of health literacy on patients' ability to access resources and supports available in the community. Since health literacy was not the variable examined in this study, I cannot rule out the possible impact of health literacy in the participants. No matter what the reason may be, participants were helpless in accessing and receiving SMEP.

The perception and experience of COPD as miserable, futile and negligent, revealed the helplessness of the participants in relation to the self-management of their disease. Due to the suffering and disability caused by the disease, they sought alternative or folk therapies from lay persons or relied on quick relief from hospital consultations. Some participants even denoted that the effective therapy was delayed and the condition of their disease was worsened. In this sense, their sympathy for peer patients consequently raised their concern for continuing the programme for helping more patients. It is because they found that SMEP as such was absolutely new to them and they had been completely neglected. A tension was highlighted between the urgent need for SMEP and the practical supply of it. More findings about this tension will be disclosed in the next sub-theme, mutual involvement.

7.2.2 Mutual Involvement

Mutual involvement is a combination of two words: 1) mutual and 2) involvement. From the face meaning of this phrase, it is easily understood as actively engaging something together. However, it is not as direct as that in the present proposition. Involvement here indicates an active view of participation in self-management, whereas mutual requires endeavour for actualizing self-management by all parties. However, mutual involvement was not inevitable unless there was active engagement to SMEP by all levels, namely individual patient, healthcare system and macro-level authority. These three levels of participation form the three categories under the sub-theme of mutual involvement. Individual obligation was discerned as that the participants recounted their own responsibility for participating in self-management in a moral sense. For systematic participation, participants were in agreement about eliciting an expectation for integrated effort of professional contribution and familial involvement in disease management. From a wider perspective, patients even anticipated the concern and policies of the government in preventing COPD and supporting COPD patients and this forms the category of macro-level participation.

7.2.2.1 Individual obligation

> Wilson : what I usually did is follow..mainly followed Nurse MN's instructions to work on it. [A72,76,14]

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> Chris : means I ate more side dishes, vegetable, it is documented in the booklet, means reducing the portion of carbohydrate. [B368,443,15]

Wilson and Chris told how they practice the instruction from the SMEP. Similar claims of compliance to self-management frequently emerged in the groups after the intervention. Kara and Aşti, (2004) suggested that increases in self-efficacy in

self-management may promote compliance to prescribed activities instructed in the education. More interestingly, participants across the three focus groups elaborated their views of self-participation as one's own obligation. They generally believed that self-management is one's own responsibility and one's own attitude of being well-behaved and cautious in relation to their own body.

SL : Then you think this is what the nurses should do?

Ivan : (.2) Not a must……

[Nick: ha ha ha]

SL : Not a must!?..Why?

Ivan: Errrr……..if you don't…if you don't take care of yourself, it's useless no matter how well the nurses teach you.

SL: I see…so you think that it is more like your own responsibility for taking care of your condition

[Ivan: Yes, myself]

[Nick: hahaha]

SL: If there are any other suggestions, or Amy?

Amy: I think the same, just like, even if Nurse MN taught you, but you don't manage yourself, then it means nothing no matter how you are taught. [A1269-1285,GD]

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Chris: Aye…on the other hand, played more attention to taking rest in daily life, for example.…there were so many examples, like stop smoking as before, now managing dietary with regard to avoiding sour, spicy and chilled food

[SL : take less carbohydrates]

Chris: …eat eat eat..less...ha...I mean those carbohydrate types, It means more behaved, we are finished if we don't behave ourselves all the now for now.

Lavin : Chilled stuffs critical

[Karen: it means a huge difference!]

Lavin: Wow, chilled stuffs are very irritating! [B743-750,GD]

Ivan hesitated for two seconds before responding to the moderator as he was potentially going to say something opposite to the stance of the question asked by moderator. I am also aware that Nick laughed out at two points of Ivan's response. Although Ivan's claim was finally supported by Amy, Nick did not comment on this idea. His laugh may imply disagreement to the statement or he indeed agreed with Ivan but he found Ivan too brave to challenge the moderator with a differing opinion. The latter might have driven him to just observe the process and tittered there. Unfortunately the moderator did not follow up with him about the reason for his laugh. Taking into account Ivan's position throughout the interview and moderator's observation at the scene, we are more confident to argue for the latter guess. This is supported by some other similar claims made by Nick.

Nick: In general, it is fine. It is indeed a matter of taking care of your own disease.....it is mainly teaching us people acknowledge the characteristics of the disease, and what do we have to pay attention, the most important thing is on us, that is all. [A199,226,8]

In the category of individual obligation, I feel strongly that the participants took full responsibility for disease management as this construct emerged across all the three focus groups. Judging the participants from the general view of constructionism (Silverman, 2011), they neither simply regarded themselves as receivers of education nor the nurses as taking complete professional responsibility for promoting the participants' health. Instead of acting as a representative of the issue and talking about it, they described themselves as part of the issue themselves. They tended to own their problem and acknowledge their responsibility. Such an individual obligation may be simply an embodied belief about the management of a chronic disease amongst the patients. Therefore, they did not just participate, but participated with a feeling of involvement and responsibility (individual obligation).

7.2.2.2 Participation in Systematic level

Since the goal of constructionist analysis is to show the meaning-making process during the interaction between interviewer and interviewees, in other words, interviewees construct aspects of reality in collaboration with the interviewer (Silverman, 2011). The following interactive dialogue clearly projected a construct of such collaboration.

Chris: This can be expanded, it will not be only one organization, e.g. let say, I am the Bureau of Health, distributing the job to each charity groups, like the unions, societies…er…apart from these, together with the promotion of flyers. Then, we could tell them our experience, what we are now, what we have been through and how we ended up like this, anyway, spell out the problem, formally to let them know. Then people with the same attitude as mine, already frustrated, those people will have a chance again, so they will be keen to join this. Then, through you guys' hard-work, more people will be saved, their lives extended, so good.

SL: If according to the ideas that you guys just mentioned, through the charity group, it is possible to arrange for the community, something about health… health education for the community concerning COPD, then actually…er...er… its… its good, its good, from what you've said, then... er..er… I want to clarify one point that maybe the content of the workshop is focusing on disease management, well, maybe based on patient, I mean…to teach patients of how to manage their... their…concentrate on their disease. Well, if it is like this, what kind of organization do you think would be suitable for doing something related to disease management?

Leon: If it is like this…well, you yourself…I mean select from the 2 hospitals…..I mean to select from nurses or doctors, whatever…I mean to take a comprehensively responsibility of this job, something like this..it's good.

Chris: Aye...your idea is good…

SL: It means action by hospital?

Leon: Well, 2 hospitals, it means like the Peak Hospital together with KWH…randomly select some staff from them, specifically responsible for this…

SL: Conducted by medical personnel, hospital to work on this type…

Leon: Yes….it would be better in this way

Karen: Can select the patients, there must be some people seeking for consultation in the hospital

SL: Yes yes yes, it mean, it is also good for conducting by hospital, can search for patients, can search for targeted patients

Christ: The target is bigger, the target is bigger, it's also better in regard to providing advice for drug usage.

SL: Because it will relate to drug usage..

Chris: Yes…yes. [B1633-1677,GD]

As for indicating a meaning constructed by a group, attention could be directed both to the assembly of meanings and to what gets assembled (Silverman, 2011). At the beginning, Chris suggested self-management education to be run on a community based mode. The moderator interrupted to hint at the 'professional' content of self-management. The group immediately converted to a hospital-based professional-run idea. More importantly, special attention should be given to Chris' change from his initial position to his final opinions. In the three responses he made after Leon's recommendation, we can see Chris' sincerity in concurring with Leon and this was particularly significant in his second response by reiterating "The target is bigger, the target is bigger…". The group highlighted the participation of professionals in bringing about self-management and had a high expectation of this. This insight was a message emerging from the contributions of the local participants interacting together in the interview. In addition, a participant's spouse also expressed her wish to be involved.

Mrs. Lee: Could I request doctors and nurses to …..=

SL: =Sure, you are now given an opportunity to express..

Mrs. Lee: Well, I'm thinking….if so….I'm also ….because after a few times of emergencies, I always think…I think, if touch wood (knock the table), what should be done?

SL: you mean the management at the time of exacerbation, you wish to learn about this, you wish nurses can teach you about this?

Mrs. Lee: Arr…I'm scared indeed, I'm just scared about this. [C688-692, 17W]

SMEP may not be merely targeted at COPD patients, their family member also play a role in it. Families were indicated to provide emotional support and can be in

themselves a strong motivator for patients to continue to live and engage with the complex requirements of self-management (Disler et al., 2012). There is a claim that self-management is a family matter and it is about all family members being able to get on with their lives, accommodating the implications of chronic health problems as a feature of everyday activity (Jonsdottir, 2013). In Chinese culture, particularly, family was indicated as a necessary support system for self-care and should be provided relevant education (Chen et al., 2008a). These studies reaffirmed the requirement to respond to the need of Mrs. Lee. On top of this, a participant tried to indicate the merit of integrating the mutual effort of the professionals and the families.

> Lavin: At last, integrated the Chest centre and those things taught by Nurse MN, in addition to my daughter's urge, is a bit effective. [B922,1087,7]

Instead of receiving healthcare service in a fragmented way, an integrated effort of all parties was valued. It is not the effects of the participation of a single party, but an organized integration of participation. This was seen as an expectation for systematic participation in COPD self-management. The next category proceeds to understanding patients' anticipation for macro-level participation in this regard.

7.2.2.3 Macro-level participation

In addition to individual and systematic participation in SMEP, the participants thought that the government should play a leading role to confront this serious health issue by supporting the implementation of SMEP. Moreover, they urged the prevention of COPD by suggesting the government put forward polices for promoting smoke cessation which was perceived as the main cause of COPD.

> Chris: It is very important for the government to play close attention to this by playing a leading role in such issue. [B1581,1847,15]

***

Ivan: For the situation as such, the government should do more promotion about quit smoking! [A1140, 1301,19]

Zhou et al.'s (2010) study made a similar conclusion that a policy-driven integrated community based intervention achieved more positive effects in preventing and controlling COPD. Participants in this study perceived the urgency for providing SMEP to COPD patients, and they also realized that its actualization requires participation systematically by the stakeholders as well as supporting policy in the macro-level aspects of a society. In this case, this could strengthen individuals' ability in accessing supportive resources and moving smoothly between different parts of the health system (Disler et al., 2012). However, in reality, the participants were being deprived of this nursing care as discussed in the previous sub-theme of helplessness. The participants eagerly hoped for concerns to be shown for the support and development of COPD self-management at the systematic and macro-level dimensions. In this sense, mutual involvement does not yet exist in Macau in relation to promoting COPD self-management. This sub-theme further explains the tension between the expectation for COPD SMEP and the absence of support for COPD SMEP in reality.

7.2.3 Support

Four dimensions of support were highlighted by the participants in relation to self-management: emotional support, cognitive input, skills building and treatment support. Participants underwent stress to live with COPD and they regarded self-management as more than some functional tactics. They think self-management means caring, valuing life and brining hope to them. Another two categories, knowledge input and skills building were the major content of the self-management intervention, participants compared their situations before and after intervention with regard to these categories. Then, regarding a nursing intervention, participants also

gave credit to SMEP for supporting their medical treatment. This will be further illustrated in the treatment support category.

7.2.3.1 Emotional support

In the following three extracts, participants demonstrated a pattern of meanings clustered for reflecting self-management as emotional support to COPD patient. Firstly, Nick stated that the provision of self-management knowledge that he previously did not come across as 'very caring' to the patients.

> Nick: It's quite good, very caring for us. We...patients don't really know those knowledge. [A854-892,8]

Karen made a further remark that to some degree she had isolated herself from help. Her saying "I then have a chance to come here" expressed her gratitude at being able to learn of COPD self-management, and in another way her sense of being valued by the nurse.

> Karen: Cause I got sick too frequent, too long. Macau is too small, I don't want to let people know that I am seriously sick, I don't have a sense to come here, she (Nurse MN) is really patient and considerate enough, I then have a chance to come here. [B1263-1321,22]

In additional to caring and gratitude, Chris emphasized that self-management provided him a new life. This indicates the hope given to the patient.

> Chris: Well, I really have died if I have not joined the workshop! Had not much hope to life
>
> [SL: haha]
>
> Chris: …It's real! I am saying the truth!! So joining the workshop provided me a second chance to my life, thanks Nurse MN (*put the palms together*)! Thanks SL (*put the palms together*) [B843,1003,15]

Support as such was recommended as it improved patients' confidence in engaging in self-management activities, because patients experiencing positive healthcare professional relationships were found to be more likely to benefit from self-management interventions (Disler et al., 2012). As the spouse of a COPD patient, Mrs. Lee also expressed her stress of taking care of her sick husband during the interview. On several occasions, Mr. Lee became grumpy when he was wheezing. Mrs. Lee said,

> Mrs. Lee: You can give me a signal ..like this…as I'm asking you questions, you can give me a sign…like this, then ah.. I know you are wheezing, so it is indeed even suffering more to be his partner. [C174-175, 17W]

***

> Mrs. Lee: So actually….Aiii….actually I have problem now (*laugh with tears in eyes*). [C506,17W]

This case revealed that the family member of the COPD patient also suffers mentally. Mrs. Lee's body language (laugh with tears in her eyes) has drawn my attention. In accord with Krueger's (1998) view on the interpretation of non-verbal communication, whether it happens spontaneously or by probing, it is important to incorporate verbal confirmation of its meaning into the analysis (Krueger, 1998). In this case, Mrs. Lee's non-verbal expression (*laugh with tears in her eyes*) reaffirmed her statement 'actually I have problem now'. Her verbal and non-verbal expression indicated a feeling of helplessness in herself and the pressing need for support. Instead of expressing all these needs for support in a rational way, the participants talked of it in an emotional way, like 'very caring', 'considerate enough', tears in eyes. Hence, emotional support emerged as a category of the 'Support' sub-theme.

7.2.3.2 Knowledge input

Giving SMEP to COPD patients inevitably involves giving knowledge to recipients. Two participants in a focus group shared their view on this issue.

> Wilson: Yes, really could learn a lot, it's all because of Nurse MN...ha ha.
>
> SL: Um…alright alright. Then what about Chris?
>
> Nick: We know what is COPD through the workshop, in the past it's not clear what kind of disease we are suffering from.
>
> SL: O…ic
>
> Nick: In the past what I know is coughing, lots of mucous..something like in the body is in the situation of heatiness, then now after attending the workshop know this is COPD..ha… [A100,110,GD]

Similar comments were also found in the other two focus groups. In Lemmens et al. (2010)'s study, COPD patients had improved disease-specific knowledge after disease-management education. This improvement was indicated in both objective and subjective knowledge, which were measured by true or false questionnaire and self-estimation of knowledge comprehension respectively. Participants in the study were not assessed by these measures, but all of them basically expressed improvement in disease-specific knowledge, and that may well correspond to subjective knowledge perceived after the programme. Furthermore, in Lemmens et al's (2010) findings, subjective knowledge was found to be a significant predictor of changes in quality of life in COPD patients. Despite that, we can tell that Amy also showed an expectation for knowledge input from the workshop, as she said "then of course, we will have….".In particular, she added "only after being taught" in her comment which possibly indicated that she perceived no other way of accessing relevant knowledge.

7.2.3.3 Skills building

Two excerpts listing below present comment from the participants about acquisition of skills when the moderator inquired about what they had learned from self-management.

Wilson: It means…taught me those, I am impressed by the breathing

[Nick: Breathing… really…]

SL: Um..breathing, about how to breath?

Wilson: It is (*demonstrating*) the breathing that involves breathing in and breathing out. [A250,283,GD]

***

SL: What have you learnt?

Lavin : Learnt how to breath.

SL: Learnt how to breath, how to breath?

Lavin: Ar….inhale with the nose…exhale with the mouth, and do it slowly. On top of that, stop carrying heavy stuffs…ar…don't carry the heavy stuffs, don't lie prone for a long time, too long would block the trachea. [B296,362,7]

Breathing exercise emerged to be the most impressive skills acquired across all the participants and constantly practiced by them after the programme. Skills listed by Lavin were for multiple purposes and were related to managing various daily activities. Lavin's eagerness to perform the controlled breathing additionally assured that the skills had been 'built in' him. As shown in Leidy and Haase's (1996) study, healthcare providers were usually seen as enablers in this instance as skills taught enabled the patients to avoid and manage symptoms, and then the patients would maintain activities from which they derive the most satisfaction.

7.2.3.4 Medical support

At least one patient in each focus group voiced the value of SMEP in supporting medical treatment as below.

> Nick: There are some, like those concerning the dosage for using the drugs (inhaler), how to use them, and got to clean up after medication, all these..all these..all these were taught.
>
> SL: O, how did Nurse MN tell you all these?
>
> Nick: By using the samples, there are so many samples by that time..
>
> SL: Ar, samples, she did it by showing you the samples=
>
> Nick: =Showed the samples, gave them to us…demonstrate to us…then we followed what she did. People like myself, never followed the instructions. In the past decade, I used the same drugs, the UFO ((Seretide)) one I've been using for 10 years= [A683,776,8]

Nick depicted that he had learned to use the inhalers correctly from the SMEP, and that is clinically regarded as especially important to COPD patients (Basheti et al., 2007). Apart from this, his statement of having used the inhalers without following the instructions for ten years is most noteworthy. It makes one question: What does it mean to a patient, his attending physician and the overall healthcare delivery in the face of such a phenomenon? Further elaboration on this issue was found in the second focus group.

> Karen: Well she taught me… in the past I inhaled that my lips…she said I inappropriately covered that thing ((mouthpiece)), cannot cover completely, then leakage, so wasted the drug.
>
> [Lavin: Sometimes I would, I saw it leaks a little bit during the time when I inhaled myself, she taught me to force it completely, use the lips to seal it]
>
> Karen: …have to cover it firmly]
>
> [Lavin: Well, that really have tried. Ar Yee ((Lavin's daughter)) scolded me several times (*laugh*).]
>
> SL: Haha…it means the inhalation skills should be correct. Har har, this is the thing that you guys remember mainly, or Chris any contents which impressed you? It means the drug inhalation skills.
>
> Chris: This one is very important, it's equal to zero if you use inappropriately. So this one⋯⋯..not did well when managing, at the beginning I⋯took it

home but couldn't……at last, after the workshop…aii! I was actually wasting lots of efforts.

[Karen: hehe]

Chris: …No wonder I always suffer from mouth ulcer! It was because I have not rinsed my mouth after inhalation, always suffer from mouth ulcer, Aii…so bad! Then, wasted for several months. [B985-1003,GD]

The patients recognized what problems they had with the inhalation technique and that improper inhaler usage caused side effects. Chris was even upset about the futile effort he put in prior to attending the workshop. In other words, patients made use of negative experiences to elicit the merits of the programme. Most importantly, Chris emphasised the significance of mastering inhalation technique by stating "it's equal to zero if you use inappropriately", this highlights the interdependent relationship between nursing instruction and medical treatment.

To sum up, support in emotion, support with knowledge and skill and in medical treatment from SMEP were identified in the participants. These were consistent with Lemmens et al.'s (2010) findings that improvements were found in medication usage and nonmedical self-care in an evaluation of COPD disease management. This perception makes explicit the difference in the participants between pre-intervention and post-intervention. After helplessness, mutual involvement and support, another emerging sub-theme 'control' will be presented in the next section.

7.2.4 Control

The participants often mentioned that they felt better control with their symptoms and their disease in general. The participants basically performed self-management in two different ways such as internalization and agency, but their level of performance was influenced by perceived incapability and interference of external factors. Whatever styles the participants adopted, they expressed sense of control to their disease and that was based on their own intention or ability.

7.2.4.1 Internalization

Bandura (1989) defined self-management as a patient integrating the learned skills into their everyday lives. Disler et al. (2012) emphasized that after integration, self-management was viewed less as a burden and rather as a facilitator to a full and active life. Internalization, in this sense, refers to the participants who can internalize the self-management components they learned into their daily activities. The participants in this study cited a number of situations that they confronted with self-management skills, for instances, adopting controlled breathing when climbing up stairs, re-positioning when encountering short of breath during sleeping, applying an action plan when having sex with partners. Extracts from Lavin and Chris showed internalization of self-management skills into their shopping experience and sex activities respectively.

> Lavin : The worse condition I've faced is one I went to Gongbei…went to Gongbeiar, it's like went out and bought something myself, then I became short of breath, but during the short of breath I thought…lean there, lean there then didn't squat down, didn't lean forward, lean on the back and breathed (*demonstrates controlled breathing*), then after a break, I use that thing and took a spray, not too long after the spray...then it became ok, then not so…not so suffered. [B511,620,7]

The above experience shows that Lavin adopted multiple strategies including positioning, controlled breathing and inhalation technique at one time. He carried them all out step by step and in proper order. When he recalled this scenario, also when he said "I thought" and he enthusiastically demonstrated controlled breathing, this may indicate his own intention to seize control over his situation through applying tactics learned in SMEP. Internalization was also indicated in another participant, Chris who applied action plan to his sex activities.

> SL: Would like to ask if you have tried following this method, action plan?
>
> Karen: I have never been in such an emergency situation…
>
> Lavin: I tried twice…
>
> SL: You tried twice…

Lavin: I tried twice.

SL: Followed the method?

Lavin: Followed the method….followed that method twice

[Chris: Are you regularly trying?]

Lavin: …I…I am not trying this regularly

SL: During exacerbation……?

Chris: I did that when I was (making love). [B866,1029,GD]

Internalization as such is the end of self-management education in accord to Bandura's (1989) definition. However, not all participants adopted internalization, some of them performed the self-management instruction selectively. This will be presented in the category of agency in the following section.

7.2.4.2 Agency

As a health behaviour building intervention, the general principle of engaging patients in self-management is of most importance. However, the category of 'agency' emerged when participants talked about their compliance to medical regimen and their implementation of action plan instructed in the workshop. Rather than seeing one as 'non-compliance', agency appears as a negotiation in the treatment of one who tries to adapt to imperfect treatment condition (Ho, 2007). It is a situation between 'autonomous agent' to 'total compliance to prescribed treatment' where one pursues freedom in drug-using. A perfect agency notion has been described as the situation where:

> *"The DOCTOR is there to give the PATIENT all the information the PATIENT needs in order that the PATIENT can make a decision, and the DOCTOR should then implement that decision once the PATIENT has made it."* (Williams, 1988, P.1183)

It is believed that medical doctors are not perfect agents and patient's preferences are ignored (Williams, 1988). However, the patient is the best judge of the value to themselves of the healthcare process and its outcome (Bryan et al., 2006). In this study, partial adoption, self-adjustment and self-modification were common approaches of agency participants have undertaken. Partial adoption emerged from a divergent case, Leon, who did not follow prescriptions of doctors nor the instructions

for diet given in the workshop. On the other hand, he shared his satisfactory experience of applying controlled breathing. These are displayed in his expressions at different point of time during the interview.

Leon: I brought the list ((old prescription)) to get the drugs myself, the doctor at the pharmacy introduced me the drug …I mean the doctor who sells drugs introduced me that.

SL: I see…I see, it means you brought those over-the-counter drugs yourself=

Leon: =Correct!

SL: So you control the disease in this way=

Leon: =Correct.

SL: Um…then..its good. You tried to look for a way to control the disease, so, it was like this before the workshop, what about after the workshop?

Leon: It is the same. [B189,231,12]

Although the moderator attempted to explore further for difference in self-management before and after the intervention, Leon firmly stated "It is the same". I thought he might be an exceptional case of opposition. However, he stutteringly made a comment as follows:

Leon: I'm most…most what…well, walking up stairs, I mean the breathe, those related to inhale and breath out were the best, that was good. [B1044,1225,12]

Leon indeed adopted the self-management teaching partially which is also an expression of agency. Due to the lack of follow up inquiry, his reason for that remained unknown. It could just be a matter of choice or based on his trust in different given approaches. Financial difficulty may also drive one to prioritise those essential disease treatments while compromising on others (Disler et al., 2012). In this sense, his behavior could be affected by financial reasons. On the other hand, I observed that he may have taboo to doctor visit. My argument for the above two reasons is based on various context where Leon stated:

Leon: For myself, I've never get sick.
[SL: Um um um]
Leon: …Have not been got sick for decades. [B470,569,12]

……I have never received any medical consultation. [B477,577,12]

…… I am not a driver, but a drudge, those for goods delivery. [B173,211,12]

…... How much is this drug? Then could this be half price or sell it to patients with a cheaper price? [B1470,1771,12]

Either reason may independently affect the patient's choice of approach in controlling his disease or both together produced a combined effect, then resulting in a partial adoption. Another way of control most patients adopted was self-adjustment. They performed what they learned from the workshop, but difficult or forgotten content were replaced with their self-adjusted way. They said :

Wilson: For those movements I was able to learn, I followed the instruction, for those I couldn't remember, I did it in free style with my own movements.

SL: In what way do you mean?

Wilson: Ha ha ha…it means those…movements that freely done by myself.

SL: Which particular style do you mean? because Nurse MN has taught you guys several movements…

Wilson: Ha, I've forgotten most of those movements…ha ha ha (*everyone laughs*).

SL: Mostly forgotten..ha ha!

Ivan: Not good at memory…ha ha ha..

SL: Because apart from those health exercise, breathing exercise, there are some others about energy saving, those movement that help saving energy=

Nick: =Yes, those technique, breathing technique, energy saving technique

SL : Those techniques, yes, those techniques, which particular you could remember?

Wilson: Ha ha…some of them can be remembered, but not much memory about them now, mostly do it myself in free-style….(*Every one laughed*)

Nick: Free-style

Wilson: Move freely [A264,291,14]

The group made adjustment to the exercise by replacing it with similar gestures. This denotes recognition by the participants of the benefit of exercise, and adjustment as such was regarded as harmless to them. A Taiwanese study also revealed that the COPD patients there tended to choose alternative methods of exercise when they encountered limitation in health condition or environment (Chen et al., 2008a). From the laughs the group made in the conversation, it could easily be presumed that they shared the same feeling in regard to their difficulty in memorizing the styles of the breathing exercise. Such laughs may also imply their embarrassment for admitting that they have forgotten the teaching content. This may give rise to a sense of guilt from being a 'poor' student. This again broke the interpersonal equilibrium within the group and this was an offence of assuring 'ren 仁' in the Confucian relationalism (Hwang, 2012). Interpersonal equilibrium is the moral goal that Chinese generally pursue in a social relationship. Furthermore, the action plan was the main self-treatment strategy delivered to the patients in the workshop. Instead of following the instruction, some patients modified the dosage recommended for quick reliever. Nick told his experiences:

SL: Umum, then do you think this method of using 4 dosages during wheezing, then 1-hour self-observation, then 4 more dosages afterward (Action Plan) is helpful..erer..when responding to the exacerbation?

Nick: (.2) Still fine…after I sprayed for 2 times I sat still, lie down, sat still, once recovered, then..then..then..no need to use it again. [A609,694,8]

Nick took two puffs of bronchodilators rather than four dosages as instructed. He showed a bit of hesitation (.2) before responding. He even tried to stress that his modified approach was effective and no addition dosage was needed. Moreover, I have identified a common attitude that self-modifying dosage according to the changes of disease was a normal practice among the patients. Special attention has to be paid on the comments made by Nick and Amy on Ivan in the following dialogue.

Ivan: I..I seldomly wheezed, I'm like..like going up slopes..like going up stairs. Once wheezed, I stopped for a while then the symptoms were gone, no problem=

Nick: =Not that serious=

SL: = Ar…just like Mrs. Au, stopped when wheezed…

Ivan: I have not tried inhaling those gases, but those with the shape as an UFO, I approximately take once every 2 days.

SL: I see, once every 2 days

[Amy: You take once every 2 days, for me it is twice per day]

SL: …Um, um, um.

Nick: (.3) The instruction is twice per day=

Ivan: =I really seldomly wheezed, only a little bit when I was going up stairs fast, not that serious.

Amy: (*low voice*) It varies between people. [A746-762,GD]

I notice a few time points in the dialogue: First, Nick's comment "Not that serious" and Nick's pause (.3) before he pointed out that Ivan was taking less dose than the instruction requested. Second, the explanation Ivan provided urgently in his last response. Third, Amy's understanding concluded for Ivan's behaviour in the end of the dialogue. It is obviously that the peer identified a medical non-compliant behaviour in Ivan in that he reduced the dose by himself. After Ivan explained about his mild condition, the group tried to interpret again by stating that it is an acceptable behaviour for mild condition. There was a general tolerance among the participants in relating to self-modification of a prescription according to one's understanding of the disease. In other words, agency was common and generally accepted among them.

7.2.4.3 Incapability

It is also noticeable that the participants also attribute their poor mastery of self-management to personal incapability. The group interaction below demonstrated this:

Lavin: =Completely memorized…completely memorized, couldn't memorize all of them! e.g. that (the gesture for the breathing exercise) that couldn't completely memorize

[Karen: O, I have totally forgotten as well]

Lavin: …I really couldn't memorize! That book…

[Karen: those styles, couldn't memorize those styles.]

Lavin: …those like that what so called 'The Dragon Sways its Tail' really don't know

[Karen: Totally forgot]

Lavin: …totally forgotten, really have this problem, confused me.. [B609-614,GD]

The group mainly highlighted poor memory to be their obstacle of practising self-management. They also tried to identify other possible obstacles in the following dialogue.

Lavin: Confusing…how to move like this, that and that (*shaking both hands*)

[Leon: we have no memories! I am like him, not even finished my elementary education.]

[Karen: then I am the same, I am the same]

Lavin: …those talk totally confused me.

Karen: We were in the village in the past =

Chris: =To learn is not emphasis on culture, these are simple stuffs =

Leon: =Well you (Lavin) and I are the oldest here..

Karen: Are you 65 years old yet? Which year were you born? [B762-766,GD]

Leon pointed out "we have no memories" and regarded this as their personal deficit in learning. Additionally, he regarded his low education level as another obstacle and Karen agreed with his comment. In contrast, there was a notable comment made by Chris who believed education level did not necessarily affect one's capacity for comprehending the content of the workshop. More interestingly, Leon and Karen just

ignored Chris's divergence and continued with the topic of age which followed on the educational issue. Ignoring this may simply imply their disagreement with Chris's opinion by avoiding direct objection which may cause embarrassment. This can be explained by the Chinese conception of '仁' (ren) which implies that one may maintain a satisfactory level of psyche and interpersonal equilibrium without causing offense as mentioned earlier in category of agency (Refer to 7.2.4.2) (Hwang, 2012). An alternative interpretation to this phenomenon is that they just found it comfortable to stay with the explanation of bad memory and low education for their inadequate mastery of certain content of the workshop. Clinical evidence demonstrated that education was associated with self-care ability and self-efficacy in hemodialysis patients (Bağ and Mollaoğlu, 2010). Increasing frequency of memory problems with advancing age, in particular, also created challenges to education for diabetic patients (Gazmararian et al., 2009). Older patients may have higher incidence of impairment to memory, abstract reasoning and coordination, consequently information comprehension and recall was diminished leading to lower compliance with complex self-management regimens (Disler et al., 2012). However, Leon and Karen were only two to three years older than Chris. An alternative explanation was that participants found that the symptomatic or psychological discomfort occurred during practising those taught exercise styles may have outweighed the anticipated satisfaction derived from them, then they chose to give up practicing them (Leidy and Haase, 1996). Notwithstanding, personal factors could probably be perceived as a barrier to harness self-management and this perception varies among people.

7.2.4.4 Interference

Apart from personal factor, external factors appeared as interferences and affected the effectiveness of self-management in COPD patients. Weather changes, air quality, smoke and gas were all interferences as they happened or appeared in a way that participants felt unpredictable and uncontrollable.

Lavin: It happened many times that it comes suddenly, means sometimes the air, or the change of weather, then the lung..became short of breath naturally. [B316,385,7]

The wording 'comes suddenly' and 'naturally' caught my eyes because it indicated a free-from-human-control nature in the environmental factors. It also presented a sense of compromising in the participants when encountering these factors. If so, environmental factors could be impersonal adverse factors affecting the overall outcome of self-management. To encounter this problem, the introduction of integrated intervention which included smoking cessation, air quality improvement, environmental tobacco smoke reduction in additional to self-management education was recommended (Zhou et al., 2010). This was definitely a comprehensive way of preventing and managing COPD.

From the above four categories, namely internalization, agency, incapability and interferences, the intention of COPD patients in seizing control on managing their disease can be seen. Participants varied in different degree in controlling their disease and their variety tended to be influenced by their level of agency on self-management, personal financial status, personal ability and environmental factors. For patients who internalized the teaching into their everyday lives, it was an ideal outcome for the programme as the participants integrated self-management activities into daily living. It is a process of internalizing external knowledge to becoming a built-in capability of the participants. Although Searle et. al.(2007) claimed that patients under self-management could implement appropriate changes under varied circumstance, changes to the dosage of prescribed medication without professional instructions appeared to be problematic. Agency as such could induce potential risk of inadequate or over-treatment in the participants. A better agency role needs to encompass patient empowerment and be based on a more collaborative approach to decision making on healthcare between patients and professionals (Bryan et al., 2006).

7.2.5 Beneficial

Participants in this study generally expressed favourable outcomes in terms of symptom control, symptom alleviation, better breathing, increased activity tolerance and more positive life view. There were categorized into three aspects of improvements and one aspect of limitation. They were bodily improvement, functional improvement, spiritual comfort and individual difference respectively.

7.2.5.1 Bodily improvement

Bodily improvement includes improvement in biological body and symptom alleviation in the participants after carrying out self-management approaches. In regard to biological body improvement, the participants believed that controlled breathing helped to expand the lung and enhance lung function.

> Ivan: I am most impressed by breathing in and breathing out, it's good for lung function.
>
> SL: I see, breathing, those involve breathing out, that's true, it's good to the lung…O…what made you having such a feeling?
>
> Ivan: It means the feeling of…you are long-term, its better now for lung inflation when taking deep breathing; In the past when I was smoking, my lung could not be expanded even I took a deep breath, now is really better, my chest expanded when I was deep breathing, I could feel it. [A321,340,19]

***

> Wilson: It is (*participant demonstrates*) the breathing that involves breathing in and breathing out. Arh..then to the lung it is more comfortable. [A260,290,14]

***

> Chris: I….about breathing, when tried working on something..e.g. making movement that need forces, walking up stairs, this breathing is mainly emphasis on breathing out, and breathing in as a supplement, breathing out longer, it mean I know my lung is deeper, with few CO2 inhalation. [B9,9,15]

The moderator followed up with Ivan's positive comment on controlled breathing and he emphasized his personal feeling of lung expansion. Wilson and Lavin indicated that their lungs were more comfortable and they could breathe in deeper during controlling breathing. Empirical evidences confirmed that controlled breathing increases tidal volumes by 500 mL and improves oxygen saturations by 2.5% (Roberts et al., 2009). These clinical changes might result in appreciable day-to-day benefit for patients. Although Roberts et al.'s (2009) review concluded that benefit of controlled breathing was only significant in moderate to severe COPD, all participants in this study commented positively to it regardless of their disease severity. It is noteworthy of Ivan's unfinished sentence "you are long term, its better now…", he might intend to state that the suggested effect on lung required a long-term practice of controlled breathing. It is not an overnight effort. Moreover, another patterned meaning emerged was how self-management approach has controlled or alleviated the 'stubborn' symptoms.

> Karen: But then the dietary, after I ate those, it was..the disease((symptoms)) was gone…not so much phlegm, not so much stuffs means controlled…mean memorized. [B695,833,22]

Karen mainly adopted diet measures to manage her symptoms, and the favourable outcome reinforced her memorizing the relevant dietary. In addition to relieving symptoms, COPD also largely impacts on mobility or activity tolerance of the patients. The meaning of how functional improvement relates to the participants is presented in the next section.

7.2.5.2 Functional improvement

An individual's mobility and activity tolerance determines his or her physical functional status. It forms one of the fundamental characteristics for a person to live as a social being. When a COPD patient is in a very severe stage, they can entirely lose this characteristic. Walking and climbing stairs are basic ability for most people, however, COPD patients suffer in varying degree from losing these abilities.

Therefore, controlled breathing is usually recommended in most disease-management programmes as its given short-term benefits experienced over a longer period in everyday life may then translate into longer-term benefits in the form of reduced exertional dyspnoea and improved functional performance (Roberts et al., 2009). Participants in this study excitingly share Ivan's experience of improving his functional status after applying self-management approaches. He said,

> Lavin: After you've learnt, it helped you breath, then followed exactly…ha…nurse MN's lesson, then I can do that, can breath. Then afterward, anyway I breath usually every day as well, at night also…at night, wake up I breath like this…practised like this, sometimes practiced like this during walking, then..it is indeed better for the lung. Usually, I…when walked around….not even for half a floor, now I can walk for around 4,5 floors.
>
> [SL: O..so great. Ar..good good]
>
> Lavin: …Really, really what a distance, not kidding!
>
> [Chris: (*Clapping hands*) Excellent, excellent!]
>
> Lavin: …not kidding!
>
> [Karen: Not really…those stuffs about breathing is really helpful]
>
> Lavin: …So it is real these things, I usually…ar, went to KWH's emergency…….the place at the outpatient… walked up to the second floor, very suffering! My kids helped me for walking up, now I can walk up 4, 5 floors by myself
>
> [Chris: Ok ok fine, U are great]=
>
> SL: =Basically what do you feel about this breathing skills no matter in the case of exacerbation or in normal situation
>
> Lavin, Karen: It's helpful, really very much helpful! [B511-540,GD]

Although the participants have not directly declared that controlled breathing improved their mobility or activity tolerance, this can be inferred from their dialogue. Lavin recounted this issue by illustrating his improvement in climbing stairs when going to the outpatient. Similar performance of doubled stair climbing was also indicated in the participants of another educational intervention for COPD patients (Kara and Aşti, 2004). Also the enthusiastic response of Chris and Karen added even more light to this achievement. Chris's comment 'Excellent excellent!' was

spontaneous and confirmed his non-verbal presentation (*Clapping hands*), hence he was sincerely showing his applause (Krueger, 1998). Their applause to Lavin's achievement reflected that they feel what each other feels and functional improvement is notably meaningful to them. Functional ability is one of the essentials for social activities. As social activities were found to be prominent in an individual's daily life and where solitary recreational activities could be performed and primary source of satisfaction could be derived from it (Leidy and Haase, 1996). A study of Chinese COPD patients also indicated that social coping strategies could help an individual reduce their psychological distress and increase their psychological well-being (Hsu et al., 2008). Therefore, functional improvement can make much difference in COPD patients.

7.2.5.3 Spiritual comfort

COPD cannot be cured and patients frequently have experiences of suffocation, inevitably there are experiences of near death and worries about life. Considering life and death issues, or specifically the meaning and purpose of life and the nature of death takes one already into the dimension of spirituality (Cockell and McSherry, 2012). Spiritual needs involve questioning like 'is life no longer worthwhile?', 'what is the meaning of life?' (Murray et al., 2004). Here below, two participants of two different focus groups provided their life view after the intervention.

> Nick: It means I understand what kind of disease we are having through the workshop, the main problems of it, so, we learnt all these through the workshop, although it is dreadful, still if you pay enough attention to all these, the lifespan is still able to be extended, can be treated well in time.. [A926,1049,8]

***

> Chris: Original was waiting for death, its finished, its finished this time, this time the journey of life stop here, face the fate…!! Then the workshop, learnt a lot, to practice those theories…ar…it was really effective! I still have few years left for my life, I still can finish something which I really want to do. [B605,733,15]

Nick and Chris are two patients among the groups in a very severe staged (Stage IV) disease. Both of them had experienced respiratory failure before participation in this study, their perception to COPD has now drastically changed from dreadful and fatal to treatable and hopeful. They presented with the belief that self-management can help to prolong their life span. No matter life prolongation would eventually happen or not, a positive life view established would sufficiently support the spirituality of these patients. It is because life prolongation did not mean prolonging suffering to them, rather they were looking forward and anticipating living life with more meaning.

In nursing, we often put emphasis on delivering holistic care where we care for the totality of a human being. According to American Holistic Nurses Association's definition (2012),

> "*holistic nursing is all nursing that has healing the whole person as its goal.*" (Thornton, 2008).

In this section, patients delineated improvement in biological, functional and spiritual aspects which covered the targeted physical, emotional, mental and spiritual dimensions in holistic nursing. SMEP thus has provided varying degree of healing for the whole person. Healing in this case does not mean becoming sound and healthy again, but refers to alleviation and attainment for best possible well-being. Nevertheless, nothing is perfectly good or free from obstacles. SMEP indeed was not beneficial in all circumstances. Limitation of SMEP was found in the words of the participants and it forms the next category, individual difference, under the sub-theme of beneficial.

7.2.5.4 Individual difference

Effectiveness of SMEP or self-management in COPD patients was believed to depend on one's disease severity and one's personal health belief across the focus groups. These two aspects vary from person to person and they largely determined

the success of self-management approaches. In terms of disease severity, COPD is a progressing chronic disease which pathological changes in the respiratory system deem to be largely irreversible (GOLD, 2013). Based on this fact, the effectiveness of SMEP may have its limitation as the disease severity of the patient increases. Relevant meanings emerged in two participants as below:

Nick: during exacerbation, you really can't do much……..You will not be ok once this kind of disease became serious, you totally couldn't stand for that when you found difficulty in breathing. [A881,1001,8]

***

Ivan: I think its sufficient now

[SL : It's sufficient already…I see]

Ivan: …seems like I can feel it, maybe I have recovered a little bit better, not as serious as him (Nick), so I think it should be sufficient. [A1076,1230,19]

Nick and Ivan were in different severity stage of the disease with Nick in stage IV and Ivan in stage III of COPD. Ivan thought the programme had helped to improve his condition and the content is sufficient to him. However, self-management approaches seemed to have made less difference in Nick's case. I particularly noticed that the participants automatically related this difference to their severity of disease. The quantitative results of this study were also inconsistent on this point as the participants demonstrated poor self-efficacy and HRQoL when the severity of their disease increased (Refer to Chapter six, Part 4). In contrast, Lefevre et al.'s (2002) systematic review suggested that benefit from SMEP was presumed more likely to be seen among asthma patients with higher baseline severity of illness. This may be due to the comparably irreversible and progressive nature of COPD. Failing in fulfilling the expectation of improvement could lead to disappointment and failure in the minds of the participants with unjustified hopes (Jones et al., 2005). It is painful to come to realize that there is a limitation in the meaningful enhancements for COPD patients that SMEP can bring. This indicates that the delivery of this programme to COPD patients should not be delayed and should be conducted at their earlier stage of the disease. On the other hand, the participants also believed that the impact of

self-management varied from person to person in accordance with the individual's concept or philosophy of health and health maintenance. Some participants repeatedly highlighted this individual difference in the focus groups, one of them said:

> Karen: My stomach can't tolerate food in cold nature, it means the food like melons those people, some people said, papaya is good for some diseases like having constipation, I can't take those. Also like banana, both food are not suitable to me, my body is like this. [B245,299,22]

Generally Chinese people in Macau have a mixture of ideas from the Western Medicine and Traditional Chinese Medicine (TCM). Relevant concepts have been included in diet instruction as suggested by the TCM physician during the development of the SMEP. Obviously, in the above extract, Karen adopted in her choice of diet the Yin-Yang theory of TCM, according to which cold and heat properties can help to regulate the pathophysiological condition of the body (Yin et al., 2012). Thus Karen believed that individual difference would induce varied effect even with the same diet. This implies that the adoption of self-management might vary from person to person under this cultural influence.

To conclude the beneficial perception and experiences of the participants derived from self-management, the pattern of positive impact covered the holistic well-being of an individual, ranging from biological, functional to spiritual improvement. This corresponds to the complex construct of SMEP which aims at improving multi-aspects of the COPD patients. However, the benefits from self-management were not perceived and happened in all participants. Individual difference in relating to disease severity and personal health belief was emerged as limiting factors to the success of the intervention. Disease severity was negatively associated with the effectiveness of self-management while one's personal health belief may filter certain self-management content which contradicts pre-existing health belief. In the following section, discussion will be made on how the theme and sub-themes correlated with each other.

7.3 Relationship of the Main Theme and Sub-themes

All the theme and sub-themes illustrated in the previous sections were not emerged exclusively in independence from each other, conversely, they were interactively correlated to comprehensively express the perception and experience of self-management by COPD patients. They were interweaving in a way that a converging message of essentiality in self-management or SMEP was prominent among the participants and among the sub-themes. A diagrammatic framework of these relationships is developed and shown in diagram 2 below.

Firstly, essentiality appears at the top of the diagram and it is related to helplessness and support on the left wing, mutual involvement and control on the right wing and beneficial sub-theme on the bottom. Secondly, self-management made COPD patients turn from helplessness to feeling supported and at the same time mutual involvement promoted control, both support and control ultimately achieve beneficial perception and experiences in

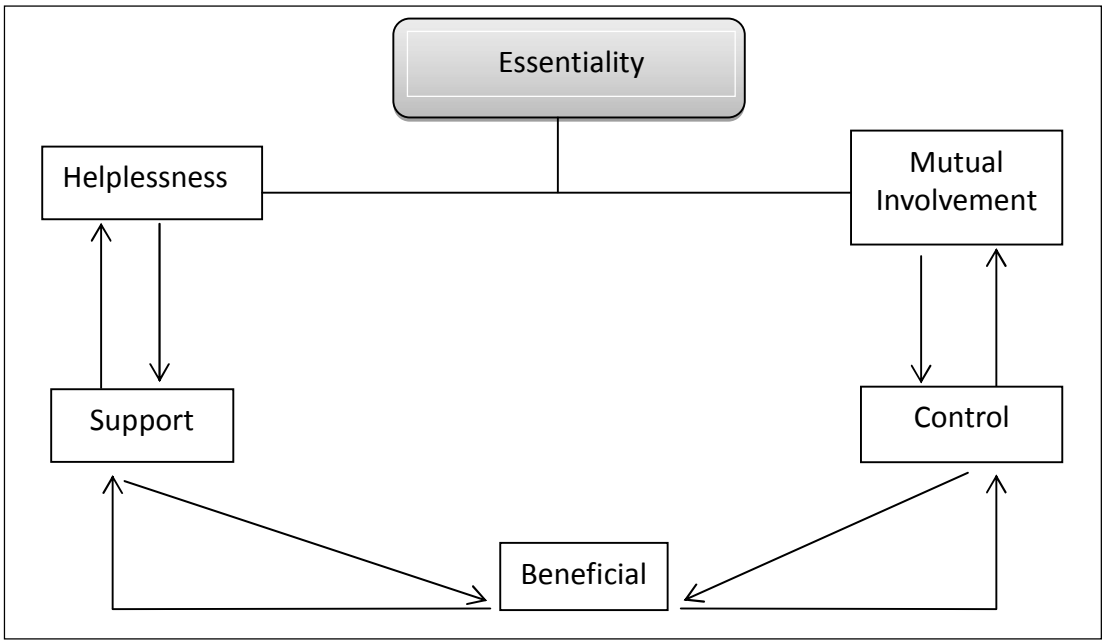

Diagram 2 Emerging theme of Essentialtiy

them. However, the variation of beneficial perception and experience could reverse enhancement or diminish their sense of support and control, and these in turn affect

the level of involvement of COPD patients in self-management or result in more helplessness in them. Due to the adverse influence of incapability, interference and individual difference on the success of SMEP, self-management is in no way taken-for granted in the participants' view. In the following sections, more elaboration, with focus group extracts, is presented to articulate the relationships as mentioned.

7.3.1 Relationship of Helplessness, Support and Beneficial

The relationship of these three sub-themes is revealed, in a way, that the more participants felt helplessness (miserable, futile, urgency and/or negligence) in managing their illness, the more support they may feel after engaging in self-management. Subsequently, they might feel that this approach was even more beneficial, and converse happens as well. In an extract provided from Chris, it explicitly displayed the relationship of these concepts:

> Chris: (.2) Before, my condition…was very serious, through the check up by doctor, it was certified…ha…certified by KWH, the coefficient my lung function was only 31, normal people is 80, so I thought it's hopeless when I knew the fact! Waited for my death at home, just a matter of time! Then afterwards learnt from nurse MN…learnt a lot, improved, in terms of improvement, in particular the dietary, in term of dietary… means I ate more side dish, vegetable, it is documented in books, means reducing the portion of carbohydrate, the intake of carbohydrate would be resulted in the production of CO_2 of the body, I know it should be very careful as mentioned here. Sometimes I took vegetable as rice. [B364,438,15]

In the first three lines, Chris expressed how miserable he was when confronted with the diagnosis and it then drove him to having a futile feeling. In the fourth line, he pointed out the knowledge support gained from nurse MN and he believed that this support improved his condition. His improvement was indicated as a spiritual comfort which enable a change from previously feeling hopeless of life to becoming actively engaged in self-management. It is also noteworthy that prior to receiving SMEP, Chris showed no anxiousness about finding coping measures. Instead, he gave up on himself by waiting for death at home. This behaviour was also suggested in Yuet et al.'s study that the psychosocial adjustment of Chinese COPD patients was indicated

to be poor. Their use of various coping strategies was moderate to low in frequency and a fatalistic coping style was generally adopted to manage their chronic condition (Yuet et al., 2002). This remarkably indicates that SMEP should be undertaken in a pro-active approach when delivered to the COPD patients. Once Chris received information about self-management from Nurse MN, he realized the essentiality of self-management to his condition, as he stated in his second last sentence that 'I know it should be very careful as mentioned here'. The 'as mentioned here' clearly referred to the information given in the workshop and he conceived it as essential to improve his condition.

7.3.2 Relationship of Mutual involvement, Control and Beneficial

Following the line of reasoning in previous section, I also noted that the relationship of the sub-themes of mutual involvement, control and beneficial were interactive in COPD patients when they adopted self-management. Basically, when the participants take part to a greater extent, they could feel stronger control on their disease and thus perceive and/or experience beneficial element from self-management. Here, through the following extract, the group has demonstrated the suggested interactive relationship:

Leon: the best part is when you are short of breath…well..well teach you to use a several pillows, that part…that gesture really is quite good…it was a bit useful, don't say it is of no use!

Karen: Useful, absolutely useful.

SL: I see..I see

Leon: Lifting up the back to …to..

[Lavin: the contrast is big!]

[Karen: Those things are in the clip]

[Lavin: If you are having those symptoms, the pillow is very important, high or low very important to breathing]

Leon: …the effect is great!

Karen: For me, since kid..I need almost 2 pillows.

Chris: I didn't feel it!

Lavin: I felt it.

Chris: I don't have experience in this, now have to learn for a bit

Lavin: When you can't breathe because of putting flat

[Karen: not working when seriously suffered]

[Chris: got to a bit higher!?]

Lavin: …the back and the breath were smoother.

[Chris: I see!]

Lavin: if it is in a more serious case then lift up a little bit

[Leon: turn on the fan during severe situation...well, taught by Nurse MN]

Lavin: …because you push against your lung, then no space for it.

[Karen: those ((turn on the fan)) depends on individual body status] [B1422-1446,GD]

In the first and second last sentences of the extract, Leon mentioned twice about the teaching from the professional where he in turn participated in it. He then internalized the tactic to his sleeping position. At this point, Lavin reported similar experiences. Both of them were even able to adjust the height of the pillow in accord to the severity of the breathing problem. This implies a sense of control in them and the participation and control gained in self-management led to the alleviation in breathing. This indicated an improvement in the biological aspects of the patients. This extract thus presents the interactive relationship suggested in the beginning of this section. Furthermore, the way Leon and Lavin spoke revealed that benefiting from such an internalized experience has strengthened their involvement and confidence in controlling the disease. Since the tactic was repeatedly commented as 'absolutely useful' and 'important', essentiality was identified to be recognized among the group for self-management approaches. Hence, Leon and Lavin were promoting the tactics persuasively to Chris and Amy. This suggests perception and/or experiences of benefits through involvement and seizing control and this positive feedback probably further stimulates one's further involvement and control in COPD self-management. Consistent with self-efficacy theory, one's performance

accomplishments produce high coping efficacy and self-capability judgment as such determines the choice of activities and performance mastery, in turn, can boost perceived self-efficacy in a mutually enhancing process (Bandura, 1982). It therefore helps to explain how beneficial perception and experiences gained from self-management enhance one's enthusiasm in participation in self-management and in control of the disease.

Nonetheless, it is noteworthy to identify the response of Karen throughout the above conversation. Although she thought that sleeping on several pillow was helpful to improve breathing condition during sleeping, she still had offered two divergent opinions in her last two comments. She stated "not working when seriously suffered" and "those depend on individual body status". In her first opinion, she tried to explain that the tactic was ineffective for severe COPD, and that means such a self-management approach could not resolve the breathing problem for all stages of COPD patients. Her response implies that the severity of disease diminished the sense of control over the disease. Another participant, Mr. Lee, also commented how disease severity affected his perception on managing his illness.

> Mr. Lee: Now the doctor said, you have already been using the best treatment
>
> [Mrs. Lee: Has done all we should]
>
> Mr. Lee: …Has done all we should, at the moment just hope it would not progress, it is impossible to get well
>
> [Mrs. Lee: Therefore, so worrying]
>
> Mr. Lee: …Then what solution do you have? You teach me, how can I still have confidence!? [C618,17]

Mr. Lee was in the very severe stage of COPD and he expressed that the disease severity prevented him from achieving improvement from any means. The expression of 'have done all we should' has raised a pessimistic emotion in the Lee couple. This in turn adversely affected their confidence in participating in the control of the illness. Mr. Lee made a frustrating remark of 'Then what solution do you have? You teach me' and this challenged the limited effect of SMEP on his relatively severe condition. Due to his belief of having used the best treatment and having done

everything, it is likely that is what causes his poor participation in any avenues other than medical treatment, and his low motivation of control over his disease with self-management measures, resulting in low beneficial perception from SMEP. This relationship is demonstrated on the right wing of the diagrammatic framework in diagram 2 above.

In Karen's second opinion in the previous extract, she thought that fanning recommended by Leon was not suitable to all patients, but was dependent on individual bodily status. What she was stating about the adaptability of one's bodily status reflected her own belief of body health balance. Having such personal belief could possibly affect her activeness in applying that particular self-management tactic. In this point of view, personal health belief demonstrated individual difference in perceiving and accepting intervention, and this affected the motivation of applying self-management approach. Therefore, individual difference as a limitation in perceiving benefits may influence one's degree of involvement in COPD self-management.

7.4 Summary

The findings of this chapter are derived from thematic analysis on three focus groups which revealed the perceptions and experiences of Macau COPD patients of self-management. As subjects of a complex intervention study, the participants of the focus groups from time to time compared their perceptions and experiences of self-management before intervention with that of after intervention. Among all data, essentiality emerged as a major theme and coordinated with five sub-themes namely helplessness, mutual involvement, support, control and beneficial. Essentiality represented what the participants perceived, experienced and eventually anticipated for COPD self-management. Initially, I laid out how the concept of essentiality authentically underlies the perception and experiences of participants in self-management. Then, I further illustrated the meaning of essentiality in other five sub-themes and how each sub-theme represents the meaning of self-management in the participants. Lastly, I have demonstrated the interactive relationship of these theme and sub-themes. When the participant perceived self-management as essential to themselves, they were more likely to feel helpless if they were not able to get access to it, otherwise it was supporting and beneficial to them. Active participation in self-management and effective control on the disease may enable the participants to perceive or experience benefits from COPD self-management. Nonetheless, there was a tension between the desire for SMEP in the participants and the provision of it in the society in reality. Incapability, interference and individual difference also appeared as limitations among the participants with regard to the possible success of self-management intervention. Mutual involvement of individuals, medical professionals, families and government in promoting and participating in COPD self-management was a future hope of the participants. In this study, a divergent case, participant's spouse joined in one focus group and she provided a different angle of COPD self-management. In future research directions, it will be valuable to explore the perception and needs of spouse or caregiver towards COPD specific disease-management. A different set of themes may emerge from this special group of participants in COPD management. All in all, belief of essentiality in self-management was found in this study as a pre-condition for successfully

promoting, implementing and practicing COPD self-management in all levels of stakeholders in the society. In the following chapter, both the quantitative and qualitative findings will be mixed and examined in relation to the research aims and discussed with reference to the established literatures.

Chapter Eight Discussion and Conclusion

8.1 Introduction

COPD is an incurable disease, but it is preventable and treatable. Historically, COPD patients in Macau have been mostly managed in the acute care setting and there is no demonstrable evidence for the effectiveness of nursing management in this patient group. This study has adopted an embedded mixed methods approach to examine the effectiveness of SMEP in COPD patients in Macau. This discussion chapter provides a meta-inference through connecting the findings from the quantitative and qualitative data. Attention has been given to proposed theoretical framework throughout the process. This chapter is divided into six distinct sections. Section one will discuss the demographic and clinical characteristics of the subjects within the study. In section two, findings derived from the illness perception and self-efficacy scales will be critically explored, with a specific focus on how these beliefs interrelate and influence self-management of COPD patients. The effects of SMEP on inhaler technique in the COPD patients will be discussed in the third section. A critical review of the biomedical findings, healthcare utilization and HRQoL of the patients after the programme is provided in fourth section. In section five, factors which were identified to have a statistical association with domains of illness perception, self-efficacy and HRQoL will be examined. Finally, I will present a conclusion of the study in terms of the significance, nursing implication, practical application and limitations of the study and potential directions for future research.

8.2 Comparable characteristics of the study samples

The recruitment rate of the study sample was 57.3%, comparatively low in comparison to those reported in previous studies which ranged from 70.8% to 84.6% (Lin et al., 2012, Bucknall et al., 2012, Watson et al., 1997). These studies also adopted similar recruitment methods of screening diagnosed COPD patients in settings of hospital, general practitioner clinic and/or community health for eligibility. In this study, however, the lack of standardized diagnostic criteria for COPD in the

clinical setting in Macau may have led to wide variation among the Macau physicians in the clinical diagnosis. This factor could potentially induce a number of 'false positive' diagnosis of COPD patients. Despite these findings, the general and between groups dropout rates were similar to those reported in previous studies (Watson et al., 1997, Monninkhof et al., 2003, Lin et al., 2012, Bucknall et al., 2012, Effing et al., 2007, Swerissen et al., 2006, Siu et al., 2007). Thus, Macau COPD patients generally presented with similar characteristics of participation as participants in previous reported COPD studies.

In terms of sex distribution, mean age and amount of smoking, the sample of this study is consistent with those demographic characteristics reported in previous COPD interventional studies (Kara and Aşti, 2004, Blackstock and Webster, 2007, Bucknall et al., 2012, Lin et al., 2012, Zhou et al., 2010). When comparing the clinical characteristics, the sample was consistent with that in previous studies in regard to year of diagnosis (Howard et al. 2009) and mean pre-BD FEV_1 and mean pre-BD FEV_1 % predicted (Bucknall et al., 2012, Howard et al., 2009, Blackstock and Webster, 2007, Lin et al., 2012, Jean, 2003, Bourbeau, 2003, Watson et al., 1997, Gallefoss, 2004), and that indicated moderate to severe levels of COPD. Despite these similarities, these participants still possessed unique factors, such as, low education, less current smokers and less concomitant diseases. These factors will be explored in the subsequent sections of this chapter.

8.2.1 Low educational levels

Most participants in this study had received either primary or lower level of education, which appears lower than levels of COPD patients in studies in Western Europe (Rootmensen et al., 2008), in the United Kingdom (Howard et al., 2009), in a region with similar culture, like Hong Kong (Siu et al., 2007) and Guangzhou city of Mainland China (Zhou et al., 2010). Interestingly, the educational levels of our participants was higher than that of COPD patients in one Turkish study (Kara and

Aşti, 2004). It could be speculated that lower educational level of Macau patients may impose effects on the learning and mastery of the content of given SMEP in them. To resolve this problem, clear and picture-based educational material with simple language and in easily understandable format was developed to reinforce patient understanding (DeWalt et al., 2004).

8.2.2 Fewer Current Smokers

This study reported a lower proportion of current smokers and larger proportion of ex-smoker than seen in other recent studies (Bucknall et al., 2012, Lin et al., 2012, Zhou et al., 2010). In other words, COPD patients in Macau are more likely to have stopped smoking before the study than has been reported in earlier studies. As smoking is one of the greatest contributing factors to the development of COPD, the participants in this study may have already actively ceased smoking following diagnosis. Another reason may be the impact of the new regime of tobacco prevention and control which took effect in Macau on 1st January, 2012 when the data collection was taken place (SSM, 2012b). Participants might have ceased smoking in response to this law before participating in this trial.

8.2.3 Less number of Concomitant Diseases

As reported in earlier COPD studies, some participants in this sample suffered from disease(s) other than COPD, but they were prone to report less concomitant diseases than reported by Bucknall, et al (2003) ($1.18 < 2.8$, SD $0.98 < 1.9$). Therefore, concomitant diseases potentially impose less influence on the Macau sample in relation to symptom-management and quality of life. However, this may also happen if their concomitant diseases have been underdiagnosed due to lack of standardized diagnostic systems in Macau.

In summary, the sample of this study shared many similarities like gender distribution, age, dropout rate, pulmonary function, year of diagnosis and amount of smoking with previous related COPD studies. Conversely, it showed a comparatively lower recruitment rate, educational level, less current smoker and concomitant disease as well as higher proportion of ex-smokers. Due to limited and heterogenous reports of working status, living conduction and medical expense payment, no conclusive discussion can be made on these aspects. Based on the general demographic and clinical characteristics of the sample, Macau COPD participants were generally found to be comparable to the COPD patients in other studies.

8.3 Relationship of illness perception and self-efficacy in self-management behaviour

The theoretical framework of this study implies that the beliefs of illness perception and self-efficacy supplemented each other to induce health-related behaviours. The following paragraphs explore and examine the findings from the IPQ-R, CSES and the correlation analysis of their subgroups against the proposed interrelationship of the two beliefs.

8.3.1 Perception of Illness identity of COPD patients in Macau

The reporting of illness identity is the process of matching somatic symptoms to an illness label. It is an expression of one's experience and beliefs about the illness symptoms (Moss-Morris et al., 2002). The sample of this study reported a relatively lower mean number of symptoms (4.69, SD=2.63) than that revealed by the COPD patients in two other studies (> 5.3, SD ±2.2 – 2.86) (Fischer et al., 2010, Scharloo et al., 2007, Howard et al., 2009). The lower education level of the participants may be associated these lower identity scores (Yan et al., 2011). Moreover, this identity dimension was seen to be positively related to reports of poor functioning, disability and inversely related to patients' own ratings of control over their health problems

(Weinman et al., 1996, Kaptein et al., 2008, Scharloo et al., 1998). The results of bivariate correlation in this study provides further support to the view that more illness identity perceived by the patients was likely to hinder their overall self-efficacy and particularly their self-efficacy in managing shortness of breath and their ability to deal with intense emotions. Perception of lower levels of illness identity in Macau COPD patients may relate less adverse effect on building self-efficacy to manage their disease.

Breathlessness was the most commonly symptom perceived in this sample, consistent with findings of Howard, et al. (2009) and Scharloo et al. (2007) studies. According to Weinman et al.'s (1996) notion, identity dimension is assessing the patient's ideas about the label, the nature of their condition, for instance, associated symptoms and the connections between them. On this basis, most patients (98%) in this study have labelled breathlessness as the main identity of their illness. Following breathlessness, sleeping difficulties (63.3%) and fatigue (61.2%) were also identified as the illness labels. COPD patients often suffer from chronic cough, sputum production or exertional dyspnoea caused by progressive impairment of pulmonary function. Chronic cough may disturb sleeping patterns and be influential among these patients. When their disease severity reaches stage III (Severe COPD) in accordance with GOLD's classification, repeated exacerbations and fatigue are prevalent in them. These were the chief complaints of patients with COPD. Surprisingly, the patients also identified pain (16.3%) and stiff joints (14.3%) which are not very commonly associated with COPD. Scharloo et al. (2007)'s study reported similar findings in 171 COPD patients who were claimed to be less sure to attribute these symptoms to their COPD. In one focus group, Winnie expressed the following view:

> "Sometimes, do you find very very painful with here (chest) when wheezing?" [B493]

If the patient has experienced some unidentified pain during the time that they are suffering from wheezing, they then tended to relate this sign of pain to their lung

problems as it appeared consistent with their breathing disorder. In relation to the symptoms of stiff joints, Mrs. Lee (Mrs. Lee's wife) mentioned the following:

> "He is kind of avoiding moving around, I'm now worrying ….I don't want to, especially lately…perhaps he suffers from wheeze…he is basically unable to walk, and just lie there. But the doctor said this is not good, you couldn't be just like that, this is what I'm worrying about him." [C347]

Although Mrs. Lee has not exactly expressed what consequences she was worrying about Mr. Lee's behaviour, it was probably condition resulting from long time restricted mobility, for instance, wasting syndrome. Stiff joint, as one of those symptoms, may be identified to be related to the outcomes of COPD. Additionally, the possibility of their lack of knowledge about the symptoms of the illness cannot be ruled out.

8.3.2 Perception of Illness representations of COPD patients in Macau

The study sample, generally, perceived COPD as a chronic, cyclic illness with serious consequences that could be controlled through treatment and adaptive personal behaviour, and they believed that they had a negative affective response and poor understanding to COPD. This finding is not fully consistent with the illness representations indicated in studies performed on COPD patients in Europe where patients reported better understanding of the disease, but had poorer personal or treatment control over their disease (Scharloo et al., 2007, Howard et al., 2009). However, this sample was consistent with the illness representations reported by Chinese patients with myocardial infarction (Yan et al., 2011). It could be suggested that this may potentially be the general pattern of perception in Chinese patients across chronic illnesses.

8.3.2.1 Perceived Timeline after Self-management Education Programme

The results suggest that participants who underwent SMEP perceived COPD to be more chronic in nature than pre-intervention. The above mid-point score (SMG 3.49, SD 0.84; CG 3.43, SD 0.84; score range 1-5) on the timeline acute/chronic dimension in this study sample showed that, in general, patients believed their illness to be permanent. It was argued that even in the natural course of having a COPD diagnosis, patients' perception of chronic timeline of their condition increases with time from diagnosis as the patients' illness experience changes (Fischer et al., 2010, Weinman et al., 1996). Fischer et al. (2010) explained that one may initially tend to perceive their health threats as acute, as a result of medical care response which is primarily focused on treatment of acute conditions, so the individual may expect illnesses to be an one-off condition. However, as time goes by, patients gradually suspect or realize that their condition may have a chronic timeline, rather than one –off acute episode. Fischer et al. (2010) supported this notion by indicating that COPD patients who were diagnosed five years or more had stronger perceptions about the chronicity of their illness. The chronic timeline of COPD patients condition grew stronger after the self-management education in this study, this may be due to the educational content on exacerbations and disease trajectory provided in the workshop, that highlighted the chronicity of COPD.

Scharloo et al. (2007) indicated that if people perceived their condition to be less chronic then they displayed better physical function. Conversely, chronic timeline perception may drive the patients to adopt a more long-term management approach rather than relying only on acute coping strategies. This may be because perception of the illness duration has directly affected the willingness of the patient to commit to changes in their lifestyles. That is, the longer the time participants anticipate the impact of the condition, the higher their specific self-efficacy to maintain a change of diet or exercise regime (Lau-Walker, 2004, Lau-Walker, 2006). This was not apparent in the bivariate correlation analysis of chronic timeline and self-efficacy in

this study. One possible reason for this may be that CSES used in this study is a general self-efficacy assessment scale and it was not particularly designed to assess self-efficacy in relation to specific dimension. However, Lau-Walker (2004)'s study on cardiac patients suggested that they perceived general self-efficacy and specific self-efficacy as quite different concepts. General self-efficacy is defined as "an individual patient's perception of the effects of physical, social, economic and emotional consequences on their life after their diagnosis "(Lau-Walker, 2004). Therefore, a patient's general self-efficacy may not reflect his or her confidence in making and sustaining specific changes in exercise or diet. In one diabetic study, Searle et al. 's (2007) further supported this point by indicating that partners' timeline representations mediated patients' levels of physical activity and dietary regimen. As this study neither attempted to assess specific self-efficacy of the patients nor their partners' illness representations, no conclusive inference could be drawn whether such an association was missed. Meanwhile, the focus group interview findings presented these relevant and insightful comments:

> Amy: Ar, don't know it is like this not until it became like this, so got to start protecting myself now. [A245,276,10]

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> Karen: I…played attention on diet, tried to avoid those food which I usually take, it exacerbated once I took those food…became more serious, then I stopped taking those food another time. [B211,255,22]

Amy expressed the urgency to adapt to a more protective mode of management after realizing the nature of the disease and her words displayed her enthusiasm to adopt such protective health measures promptly. Karen wished to alter her dietary habits to avoid progression of her disease. They both sensed that they still have to live with their COPD for a long time, and as such they tended to respond to it with readiness adopting appropriate changes in their lifestyle as required. These comments reflect a level of confidence in making such specific behavioural changes. Nonetheless, an alternative explanation for the lack of

correlation between chronic timeline of illness and self-efficacy is that the self-efficacy of COPD patients in Macau is predicted by factor(s) other than the duration of timeline of the condition.

8.3.2.2 Perceived Personal control after Self-management Education Programme

Instead of improving the personal control of COPD patients through SMEP, my data showed that those patients who were not allocated to the interventional programme significantly perceived themselves to have less personal control over their disease. Fischer et al.(2010)'s study indicated that perception of personal control in COPD patients decreased over time. They argued that as the disease progresses steadily over the years, it is usually associated with more intense symptoms and more frequent exacerbations and disease-associated disability. Therefore, COPD may potentially impose increasingly difficulties on patients to perform or cope with daily activities. This may lead patients to gradually lose confidence in their ability to control the illness. Provided the disease severity of the participants of both SMG and CG were homogeneous and they were under same length of time for follow-up, participants in CG perceived significant lower personal control at the follow-up assessment while those in SMG remained unchanged. SMEP, in this case, may still have helped to maintain or sustain the patients' losing confidence in personal control over time. However, perception of personal control in uneducated patients appeared to diminish naturally. In addition, perception of a low sense of control appears to be associated with poorer outcomes, exemplified by, functional status, disability, depression and anxiety (Kaptein et al., 2008, Scharloo et al., 1998). The bivariate correlation analysis in this study also demonstrated similar findings that the more one perceived better personal control the more confident one could be confronting physical exertion. Lau-Walker (2004) reported corresponding results that patients who felt capable of controlling their situation were more likely to show high general self-efficacy and also high self-efficacy specifically in exercise which requires physically exertion.

One patient in the focus group who proclaimed herself to have a stable and controlled condition of COPD made the following statement:

> Winnie: I just feel better this year, when I carry one whole bin of trash in previous years, cos I'm a cleaner, I had to stop and rest for two to three times when I carried a bin of trash…carried to the corner of the street, really
>
> [SL: Feel better this year..]
>
> Winnie: …feel much better this year. [C92,9]

The qualitative data in this study supports and enhances a better understanding of the bivariate correlation quantitative findings in this study. The previous quote highlights that when the participant felt of in control of their condition, she identified appropriate activities for improvement. The physical sensations that patients experienced can be used as a sensory information to alter their representation of the event (activity of physical exertion) and coping process (Johnson, 1999). Therefore, it may be equally important to provide informational material as well as experiential instructions in the SMEP as this may help to enhance the patients' sensations and confidence in performing activity of physical exertion.

8.3.3 Perception of causal attributions to COPD in COPD patients in Macau

Causal attribution analysis has rarely been reported and often been neglected in COPD research which has employed self-regulatory theory or self-perception theory (Howard et al., 2009, Fischer et al., 2010, Kaptein et al., 2008). Macau COPD patients were more likely to attribute immune factors and risk factors more to their disease than psychological factors or by chance. This was quite different from the findings in Scharloo et al. (2007)'s study. Own behaviour (own behaviour and smoking) and psychological causes (i.e. stress, mental attitude, family problems, emotional state, and personality) were the commonest perceived cause of COPD than immune factors and by chance. It is worth noting that the same tool for assessing this causal dimension was not used in this study. The own behaviour subscale used in

Scharloo et al. (2007)'s study was integrated with a larger risk factor subscale used in the current study. In this sense, patients in both studies believed that external factors (i.e. risk factor) were the main causes of COPD while Macau patients tended to attribute their COPD more to physical reason (i.e. immune factors) than to psychological factors. These perceptions remained generally consistent before and after participation in the SMEP.

An altered immunity, pollution and ageing factors were the three causal attributions most strongly as individual causative factors believed by the participants throughout the study. These were closely followed by smoking and overwork. However, after SMEP, more participants tended to report smoking as attributable to the development of their disease and less patients reported "don't know or never thought of". These findings are in contrast with studies by Hoth et al. (2011) and Scharloo et al. (2007)'s studies where smoking and own behaviour were perceived as the main causes by the COPD patients. Improved cognitive understanding of causal attributive belief after SMEP implies that patients who reported "don't know or never thought of" prior to the commencement of the study may be due to inaccessibility to disease-related information or uncertainty about the stated propositions. Their low educational level may have hindered their access to and appraisal of information. 'Optimistic bias' was indicated in Hong Kong Chinese to affect their perception of risk of coronary health disease, this optimistic bias may also have existed in this sample (Chan et al., 2011). 'Optimistic bias' or 'unrealistic optimism' refers to people who tend to underestimate their own risk of disease. On the contrary, we cannot exclude the responsibility of the Macau healthcare workers in Macau to provide appropriate disease-related information to these patients. As the principle researcher, observations revealed that most patients were neither told the proper or full name of their diagnosis nor disclosed of diagnosis in an open manner. This might potentially mislead the patients into adopting a less attentive way of confronting their chronic illness.

Nick: then now after attending the workshop know this is COPD. [A109,120,8]

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Nick: Umum…if not that I didn't pay much attention to this disease before, and I also didn't know the severity of it. [A932,1057,8]

COPD patients in Macau appeared more prone to attribute external (pollution) or uncontrollable factors (i.e. altered immunity and ageing) to the onset of their condition. Conversely, patients in Hoth et al. (2011) and Scharloo et al. (2007)'s studies attributed own self's behaviour as the main attribute. It may be speculated that a comparatively large proportion of participants in this study ceased smoking before study participation and their COPD has not subsequently resolved. These individuals may be more likely to attribute their illness to external or uncontrollable factors. Alternatively, patients may simply deny or avoid their own personal responsibility for causing their disease, and be embarrassed to confront or admit any wrongful behaviour. In relation to these findings, two patients in different focus groups stated,

Leon: For myself, I've never get sick

[SL: Um um um]

Leon: Have not been got sick for decades, It was since...now I mean before the workshop I went to KWH, that time, maybe went out to those road, cause I am a delivery worker, inhaled some dust, together with smoking, it then became like this. [B470,569,12]

***

Nick: This is, this is a kind of environmental problem, related to pollution, some related to job duty, some related to smoking. [A818,929,8]

Under the influence of Confucian relationalism, Macau Chinese COPD patients might try to restore 'face' by pulling in various causal factors other than own risk behaviour. 'Face' is a kind of 'social contingent self-esteem' which is diminished through negative social evaluation of one's social or moral acts and vice versa (Hwang, 2012). Hoth el al. (2011) suggested that attributions about the cause of

COPD may be particular important for one to determine their disease management approach. Therefore, it is crucial to provide understandable, 'face-protecting' and evidence-based preventive information in the educational programme to assist them to effectively avoid the attributing factors of their disease.

8.3.4 Relationship between Illness perception and Self-efficacy

Quantitative analysis of the eight illness representations with subgroups of self-efficacy revealed that improvement in three dimensions (personal control, treatment control, illness coherence) and the reduction in four dimensions (identity, consequences, timeline cyclical, emotional representations) of illness perception are more likely to enhance self-efficacy in general, whereas 'timeline' did not demonstrate association with all aspects of self-efficacy. Discussion on 'personal control', 'identity' and 'timeline' received critical review earlier in this chapter, the association of the other illness representation variables and self-efficacy will now be discussed in this section. Improvement in the perception of 'treatment control' in COPD patients is found to be more likely to improve their confidence in managing negative effect, intense emotions and physical exertion and general self-efficacy. In other words, patients may perceive that the treatment controllability helps with the management of exacerbation, to stabilize emotions and to tolerate physical exertion. Howard et al. (2009)'s study stressed that individuals reporting a greater impact had apparently less perceived control of the treatment for COPD. This study demonstrated that when the patients perceived a better understanding of their illness (i.e. illness coherence), they were more likely to have confidence to manage exacerbations, stabilize their emotions, avoiding adverse effects of weather or environment, abstaining from behavourial risk factors and generally manage their disease more appropriately. Sense of coherence to the illness was regarded as the self-management resource which most likely fosters persistence in older COPD patients in chronic illness situations, so that in facing of ongoing issues related to COPD, sense of coherence and self-efficacy together may enable patients to find their lives comprehensible and manageable (Warwick et al., 2010). A consensus for

this relationship was constructed by this example of a dynamic conversation in a focus group:

SL: Then does this workshop is really what you guys needed?=

Nick: =It is needed, needed, at least, there is quite a lot of knowledge that we need to know, not everyone understands this disease

[Ivan: Yes, yes]

Nick: …at least some one should understand, meanwhile there are some skills, how to control the nutrition, how to manage during exacerbation and emergency situation, have some knowledge about this.

[Ivan: It means…it means the nurses.…it means there is someone there introduce us of how to understand the illness condition, and how to adapt myself to the disease, it's quite good.]

Nick: At least I know what's going on, you know we know nothing about medicine.

This quote stresses that improvement in understanding the illness has strengthened the participants' confidence in adapt more appropriately. Meanwhile, this study found that a strong belief in the more severe consequences and cyclical nature of the illness was related to poorer self-efficacy in the participants. This is consistent with a study by Lau-Walker (2004) which revealed that patients reporting a greater impact of the illness had significantly lower self-efficacy to cope with the condition. Moreover, this present study indicated that COPD patients experiencing strong emotional upset for their illness hampered their general self-efficacy and self-efficacy in managing exacerbations, stabilizing emotions, abstaining behavourial risk factors. Together with the strength of correlation, illness perception belief and self-efficacy appeared to associate in most aspects moderately to determine health-related behaviours of COPD patients. Therefore, this study on one hand provides supporting evidence for possible relationship between illness perception and self-efficacy beliefs in guiding health-related behaviours in COPD patients after it was initially proposed in cardiac patients and diabetes patients (Lau-Walker, 2004, Lau-Walker, 2006, Bean et al., 2007). On the other hand, it indicates that each belief holds some elements independent from each other but essential to guide health-related behaviours. Nonetheless, conclusive inference about their causal

relationship cannot be made from bivariate correlation analysis in this study. Multivariate analysis with a larger sample is suggested in further research in this area.

8.3.5 Self-efficacy of COPD patients in Macau

One of the primary aims of this study was to improve the self-efficacy of Macau COPD patients to enable them to manage their illness and daily living through implementation of SMEP. In the post-trial follow-up assessment, the patients allocated to educational intervention showed greater improvement in general self-efficacy and three aspects of self-efficacy (intense emotional arousal, physical exertion and weather/environment) than the control group. Results from earlier studies have varied in relation to SMEP or cognitive-structured education improving self-efficacy in COPD. Bucknall et al. (2012) and Lemmens et al. (2010) indicated no evidence about improvement of self-efficacy through self-management education. However, several COPD studies have demonstrated varying aspects of self-efficacy improvement for patients (Kara and Aşti, 2004, Wong et al., 2005, Stellefson et al., 2012, Davis et al., 2006). One RCT study reported significant improvement in total and all subgroups scores of CSES in experimental group at post-education and after one month follow up (Kara and Aşti, 2004). Lorig and Bandura (2001) and Siu et al. (2007) achieved improvement of self-efficacy in managing chronic illness, like perform self-management behaviours in COPD patients at one week and maximum two years respectively after self-management education. Improvement solely in functioning aspect (i.e. walking and physical exertion) was indicated in two studies (Wong et al., 2005, Davis et al., 2006), these findings are consistent with the findings of this study.

Discrepancies in the overall findings of the effects of self-management education in COPD patients' in relation to self-efficacy among studies may be attributed to several reasons. The lack of standardization for the content or structure of

self-management education, different measurements used for self-efficacy assessment (Stellefson et al., 2012). In this study, three aspects of self-efficacy showed improvement in the experimental group, this provides encouragement for several reasons. Firstly, patients express higher confidence in encountering or avoiding difficulty in breathing when they had adverse emotion, for example, fear, anger and anxiety. This concept also emerged among participants in a focus group:

Mr. Lee: I don't have those emotions, I'm not anxious, I'm not so..

[Winnie: (*hehehe*) Mr. Lee is similar with me, I'm not anxious too]

Mr. Lee: …I don't even have pressure, I have nothing of so

[Mrs. Lee: (*laugh gently*)]

[Winnie: I only have problem when I climb up staircases, I would wheeze a bit ….quite a bit when I carry heavy stuff.]

SL: That means you don't have problem with emotion.

Winnie: I don't have temper (*haha*)

SL: is calm….no temper..

Winnie: I don't have temper (*hehe*) [C343,GD]

They mainly thought that periods of intense emotion did not bother them as they do not have fluctuating emotions or they took an easy mind to live a relatively relaxed life. However, they were generally more concerned about managing an activity that demanded exertion. Secondly, the experimental group in this study reported higher levels of confidence than the control group in relation to avoiding breathing difficulties during physical exertion. Self-appraisal of efficacy is enhanced by selective recall of past successes, whereas reduced self-appraisal of efficacy appears to be linked to recall of failures (Bandura, 1989). Data from the qualitative interviews highlights that the patients had applied some strategies taught in the workshop and had successfully coped with physical exertion events, this may explain the reason for higher self-efficacy levels in the physical exertion subgroup indicated in the follow-up assessment. Relevant quotes from the focus groups have been referred to the 'Functional improvement' category of the theme 'Beneficial' in the qualitative findings chapter. Most importantly, application of self-health behaviours

with success in various situations of everyday life may let patients feel more energetic and further enhance patients' sense of self-efficacy which in turn leads to better disease control and improve better patient outcomes (Bourbeau and van der Palen, 2009, Siu et al., 2007).

Weather or environmental factors are the known risk factors for COPD (GOLD, 2013). Thirdly, quantitative results in this study demonstrate that COPD participants felt little confidence associated with the effects of weather changes and environmental triggers in relation to their disease. Given that part of the teaching content of the SMEP focused on specific coping strategies towards dealing with weather changes or environment hazards, the patients may have learned and put into daily practices. This can be explained as self-efficacy governs the interrelationship between knowledge and action (Bandura, 1986). A participant in the focus group described:

> Chris: For me I mainly followed the instruction for breathing, and also to avoid…mean those tobacoo, or those temples, or those car park, those related to exhaust, tried hard to avoid all these factors. [B296,489,15]

According to Chris' description, environmental adverse effects are triggers for exacerbations for COPD patients. With regard to confidence in managing breathing during weather changes, the participants expressed concerns towards the threat of adverse weather conditions upon their health condition. When they were asked about the content learned from the SMEP, they responded:

> Nick: …weather is cold, most important is to keep yourself warm when the weather is cold, don't caught a cold, it's not ok once caught a cold.
>
> SL : I see..this is important as well, the method of self-protection.
>
> Nick: Cause coughing…once you cough, you are infected, the solution to infection nowadays is taking antibiotics, in addition we are now at 'high risk' weather, will be very dangerous once got sick. [A904,1021,8]

Hence, any measures that were instructed in the SMEP that assist to manage or relieve the suffering caused by triggers could have been perceived as supportive. Interestingly, SMEP appears to only affect the perception of 'timeline' and 'personal control' in the participants and they showed limited association to the self-efficacy variables. This may imply that in some way SMEP might have directly enhanced self-efficacy of the COPD patients without the mediation of illness perception. Due to the potential association of illness perception and self-efficacy, it is recommended that further SMEP should integrate more elements of imparting the illness perception so as to foster better self-efficacy in the COPD patients.

To conclude this section, SMEP appears to give COPD patients in Macau perception of a more chronic timeline of their condition, this may enhance their willingness to engage in more healthy behaviours. In addition, SMEP appears to maintain patients' perception of personal control, which may decrease over time and this tends to improve patients' self-efficacy in managing physical exertion. Moreover, SMEP can improve patients' general self-efficacy and self-efficacy in managing intense emotions, physical exertion and weather/environment effects. With the exception of timeline perception, all other dimensions of illness representation showed association with patients' self-efficacy in managing their illness. The greater the number of symptoms perceived, the longer the duration of the illness, the stronger the cyclical nature of the illness perceived, the stronger the emotional representation of the illness, the participants perceived lower self-efficacy in managing COPD. Alternatively, the stronger the perception of personal control, treatment control and illness coherence, the participants perceived better self-efficacy. On one hand, this study provides further evidence to support the relationship of illness perception and self-efficacy beliefs in establishing health-related behaviours among the chronically ill. On the other hand, the SMEP developed in this study has to some extent directly enhanced the self-efficacy of the participants, rather than through changing their illness perception. This may be potentially due to inadequate integration of promoting illness perception element in the development of SMEP, or the participants' background of low education affecting their ability to cognitively understand the

teaching aspects of the programme and consequently their illness perception remains largely unchanged.

8.4 Effects of Self-management Education Programme on Inhaler technique of COPD patients

Inhalation therapy is a common mode of treatment for COPD patients, however, incorrect use of inhaler devices is not uncommon among them and is usually due to problems with comprehension or coordination(NAC, 2008, Vincken et al., 2010, Australia, 2008). Consistent with the findings of previous relevant COPD educational studies, SMEP appeared to lead to improved inhaler technique of COPD patients in my study (Lemmens et al., 2010, Hämmerlein et al., 2011, Basheti et al., 2007). Nonetheless, amongst all available inhaler devices, patients using MDIs were found to have made more inhaler technique mistakes than those using other devices (Hesselink et al., 2001, Melani et al., 2004). MDI users were also found to be less likely than DPI users to be adherent to their inhaled therapy (Roy et al., 2011). This finding was also discussed in Hesselink et al.'s (2001) review that patients using MDI tended to fail to synchronize inhaler actuation with inspiration (for instance, hand lung co-ordination) and patients stated preference toward using dry powder inhalers. Patients confirmed this view during one of the focus groups.

SL: Which steps are difficult for you to comprehend? What do you think?

Winnie: =I think using ventolin ((MDI device)) is very difficult to inhale, mine ((Turbuhaler)) is very easy to inhale. See, inhale….mine ((dry powder inhaler)) is (demonstrate) inhaling one dose like this, mine is.

Mr. Lee: Yours need not to press for the dose?

Winnie: No.

Mr. Lee: See see…let me have a look.

Winnie: Next time, you request…that that ..doctor prescribes this one to you, really very good, better than your ventolin ((MDI device))! [C536-542]

In this quote from the focus group, Winnie's enthusiasm towards introducing the dry powder device and Mr. Lee's interest in knowing it possibly indicated the need for

more user friendly devices. A user friendly device may enhance their confidence and ability to comprehend efficient inhaler technique which in turn potentially improves the effectiveness of the treatment in terms of perceived control (Basheti et al., 2007). It was found that the type of inhaler was the strongest determinant associated with incorrect inhalation technique (Hesselink et al., 2001). Moreover, ageing, negative emotions or emotional problems (e.g. shame, helplessness, dependency, restlessness, temper, confusion or depression) were more likely to induce incorrect inhalation technique in COPD patients (Hesselink et al., 2001, Vincken et al., 2010, NAC, 2008). Importantly, although there was not a statistically significant decline in the inhaler technique in SMG patients between post-intervention assessment and six month after intervention, there was a slight clinical decrease in the mean mastery rate of inhaler technique. Similar findings was reported that such decline happened over time and was associated with a decrease in some disease outcomes (Basheti et al., 2007). One-time intervention was not sufficient for all patients to fully harness error-free inhalation technique (Hämmerlein et al., 2011). Repeated instruction is recommended as it appears to be associated with good adherence to the inhalation regimen and this related to less exacerbation and better quality of life in asthma patients (Takemura et al., 2010)

In summary, SMEP in this study demonstrated favourable outcomes relating to mastering inhaler technique, which may in time influence adherence to inhalation therapy, disease control and disease-related quality of life of COPD patients. As for supporting long-term mastery of inhaler technique over years, this study data could not provide a definitive conclusion and a large scale longitudinal study on evaluating the long-term effect of self-management education on the mastery of inhaler technique is recommended.

8.5 Effects of Self-management Education Programme on biomedical outcomes, healthcare utilization and health-related quality of life of COPD patients

In addition to examining the primary outcomes of SMEP, some secondary outcomes were examined in this study and these demonstrated significant improvement for COPD patients and included less days of hospitalization and better disease-specific health-related quality of life. The following section provides an overview of these secondary outcomes in relation to current established literature.

8.5.1 Pulmonary function

Improvement in pulmonary function with statistical significance for both SMG and CG was seen in the present study, however, this was deem to be clinical insignificant. It is because the size of variability of FEV_1 between the two time point assessments was less than 12% and 200ml. This limited variability may indicate a presence of fixed airway narrowing in COPD patients regardless of the effects of the intervention (GOLD, 2010). The absence of clinical improvement in pulmonary function of COPD patients on a SMEP is consistent with reports from systematic reviews (Adams et al., 2007, Effing et al., 2007, Monninkhof et al., 2003). One rationale for this outcome is that SMEP is not intended to act as a curative intervention, it however may have limited effect on reversing the accelerated decline in pulmonary function in COPD patients who are in a chronic disease state and bearing characteristic of irreversible airway limitation (Monninkhof et al., 2003). A study participant made the following comment on his pulmonary function:

SL: Um…got it, got it. May I also ask you? What do you feel about your lung function in the past six months? Better or worse?

Mrs. Lee: Should be worse

[Mr. Lee: So so, not really worse]

[SL: Persisting]

Mrs. Lee: …still weak.

SL: Still weak, still persisting…er er…that means similar to that before the workshop?

Mr. Lee: So so.. [C82-86]

Despite that, the improvement in the pulmonary function of the self-management group in this study showed no poorer benefits in relation to pulmonary function of COPD patients than that indicated in the trial of comparing the combination therapy of long-acting bronchodilator and inhaled corticosteroids with placebo (Aalbers et al., 2002, Calverley et al., 2007). In TORCH (Towards a Revolution in COPD Health) study (2007), the mean FEV_1 in the combination-therapy group demonstrated an increase of 29ml and an decrease of 62ml in the placebo group, resulting a net improvement of 91ml in the combination-therapy group. Whereas the participants of this study demonstrated an net increase of 128ml in the median FEV_1 after receiving SMEP. (Calverley et al., 2007) (Refer to table 14). The extent of increment in the pulmonary function of the COPD patients after SMEP may be due to the effects of their significantly improved inhaler technique which could enhance the effectiveness of the treatment (Basheti et al., 2007). This could happen as the baseline mastery rate of inhaler technique of the participants of this study was less than 60% with some even using it incorrectly.

Nevertheless, improvement in pulmonary function is not intended to be the sole aim of SMEP. Clinical evidence suggests that this form of intervention may work better as part of a multi-component approach. They may include delivery system design, decision support, and clinical information systems. This combination of approaches has demonstrated greater improvement in pulmonary function than implementing self-management education alone (Adams et al., 2007). Therefore, SMEP has not brought direct benefit to the pulmonary function of Macau COPD patients, however, further studies in exploring the exact effects of a multidisciplinary organized chronic care model on the pulmonary function of COPD patients are recommended.

8.5.2 Healthcare utilization

The findings of the study suggested that SMEP reduced number of days of hospitalization, despite this it did not reduce frequency of using rescue medication and numbers of unplanned emergency room or outpatient visits. These findings are more in line with previously reported results in the majority of similar studies (Adams et al., 2007, Monninkhof et al., 2003, Swerissen et al., 2006, Bourbeau, 2003, Bucknall et al., 2012). Educated patients have been found to be less likely to suffer from exacerbations compared to patients in the control groups (Rootmensen et al., 2008, Zhou et al., 2010). The aim of using an action plan was to lead to increased ability for COPD patients to recognize and react appropriately to an exacerbation, but current best evidence does not show any association between these effects of self-management intervention with reduction in healthcare utilization in patients with COPD (Walters et al., 2010, Bourbeau, 2003). This phenomenon is illustrated in the following extract:

Amy: =I am the same. Having no knowledge before the workshop, went to the emergency when it happened, got to go to the emergency immediately when it happened.

SL: Go to the emergency immediately when it happened. What about now?

Amy: I don't scare now…he..

SL: Don't scare now means..?

Amy: Cause no need to go frequently to the emergency now, it the past, it's almost like around a week, really=

SL: =What are the reasons?

Amy: It means maybe I am now taking medicine, and doing those breathing exercises, those, I changed a bit of others. It's not easy to get cough or short of breath once changed.. [A1080-1117,GD]

Amy showed her belief that what she has applied from learning in the workshop has helped her in reducing exacerbations and thus reduce healthcare utilization. However, in Adams et al.'s (2007) systematic review, multiple chronic care components were found more likely to demonstrate significantly shorter hospital length of stay than

single self-management intervention. Of special significance is the evidence that, reduced utilization was associated with the improvement in perceived self-efficacy in COPD patients (Lorig et al., 2001). As there was an improvement in the perception of self-efficacy in the SMG in this study, participants may feel more confident and better prepared to manage the periods of stability and exacerbation of their condition. Additionally, this sample was largely recruited from a private hospital where patients had to pay for care. Due to additional financial burden, it is speculated that patients may be more likely to reject hospitalization or request early discharge once the acute stage has overcome to avoid additional costs.

8.5.3 Health-related Quality of Life

Previous studies have indicated that SMG could improve the symptomatic domains of disease-specific HRQoL (Zhou et al., 2010), however usually it had little impact on the general aspects of HRQoL (Effing et al., 2007, Monninkhof et al., 2003, Bucknall et al., 2012, Lemmens et al., 2010). This would also appear to be the case in this study. These associated ideas were expressed in the focus group:

> Wilson: =Right, now with the skills that taught by Nurse MN…it is like, if suffering from walking…ar…control the breathing
>
> [Nick: (*Murmur*) The breathing skills]
>
> Wilson: …take a rest, then physically comparatively better, then not..not…not so, you know.
>
> SL: So, you have learnt some breathing and resting skills =
>
> Wilson: =Hehe…yes…if there is no one to teach you, you will not know how to relieve the symptoms, after the workshop then you know how to relieve, like controlling the breath, and taking a rest, then it becomes fine afterward. [A1003,1142,14]

In other studies, significantly higher HRQoL scores have rather been seen in the activity domain in the educational group (Monninkhof et al., 2003). It was suggested that cognitive processes imposed direct influence on quality of life since direct relations between knowledge gain and investment beliefs (independent variables) and quality of life (dependent variable) were found (Lemmens et al., 2010). Of particular

significance is the evidence that, even though disease-specific HRQoL improved, COPD patients do not demonstrate improvement in generic HRQoL after self-management intervention (Lemmens et al., 2010, Monninkhof et al., 2003). This may be due to the relatively higher baseline scores in the generic HRQoL scale than that revealed in previous study (Desikan et al., 2002) and that could have underestimated health status assessment of the participants of this study (Sato et al., 2004). Alternatively, disease management for COPD bears a multidimensional and multidisciplinary nature and takes time to detect changes. The six months follow-up period may have been too brief to observe quality of life improvements resulting from the intervention (Lemmens et al., 2010). Therefore, SMEP in certain extent may improve specific aspects of quality of life of COPD patients.

8.6 Factors affecting illness perception, self-efficacy and quality of life of COPD patients

It is important to identify factors that may enhance or hamper the outcomes of self-management intervention in order to improve the effectiveness of this type of intervention. Among all variables, clinical characteristics (Stage of disease, post-BD FEV1% Pred., long-term treatment, prescribed MDI and frequency of using SABA) rather than demographic characteristics of the participants revealed a relationship with illness perception, self-efficacy and HRQoL. These results indicate that clinical characteristics could have a stronger influence than demographic factors on psychosocial conditions in COPD patients living in Macau. In addition, psychosocial characteristic (self-efficacy) was also associated with the levels of HRQoL. Thus, patients with more severe disease condition and under long-term treatment may have perceived more serious consequences and lower levels of HRQoL. When perceived self-efficacy is higher, overall HRQoL is more likely to be better.

In previous studies, the relationship between patients' illness perception and demographic and clinical characteristics remains controversial (Lau-Walker, 2004, Lau-Walker, 2006, Bucknall et al., 2012, Fischer et al., 2010). Howard et al. (2009) and Lau-Walker (2006) supported that both demographic characteristic and clinical

characteristic were inversely related to the perception of illness nature or illness impact in the patients. Meanwhile, this study only demonstrates association of illness perception with clinical characteristic. In contrast, such relationships were not revealed in other studies (Bucknall et al., 2012, Fischer et al., 2010). In spite of the ongoing debate about the relationships between illness perception and these factors, Lau-Walker's (2004) study on cardiac patients found that those with severe illness condition perceived their illness consequences more negatively, resulting in being more capable of responding effectively to self-management interventions (Lau-Walker, 2004).

Kohler et al. (2002) supported the findings of this study that clinical characteristic (pulmonary function) correlated with self-efficacy and HRQoL, and self-efficacy also correlates with HRQoL of COPD patients. However, the correlation between pulmonary function and HRQoL were modest, much of the variance in the latter was not explained by clinical characteristics (Jones and Kaplan, 2003). On top of that, the strength of these relationships was found to be unstable as psychosocial variables have shown to have stronger influence than biomedical variables on HRQoL in the patients after the intervention (Kohler et al., 2002). Their analysis suggested the relationship between HRQoL and pulmonary function varied depending on a person's level of self-efficacy for specific activities. This change could be identified in the following conversation extracted from one of the focus group participants.

Chris: Before, my condition…was very serious, through the check up by doctor, it was certified…ha…certified by KWH, the coefficient my lung function was only 31, normal people is 80, so I though it's hopeless when I knew the fact! Waited for my death at home, just a matter of time! Then afterward learnt from nurse MN…learnt a lot, improved, in terms of improvement, in particular is the dietary, in term of dietary..means I ate more side dish, vegetable, it is documented in books, means reducing the portion of carbohydrate, the intake of carbohydrate would be resulted in the production of CO_2 of the body, I know it should be very careful as mentioned here. Sometimes I took vegetable as rice.

SL: =I see…taking more vegetable now.

Chris: Yes

[Leon: You are great!…It is the worst that I..I..I never take any caution in dietary.]

Chris: Secondly, secondly as said before…in term of dietary; secondly is..is…is, ar do some exercises in the morning after wake up, those taught us the style of "The Dragon Sways its Tail" those type, finished all of them, but recently, recently I have stopped because of the hot weather, since I scare of being heated up, on the contrary, I am not afraid of cool weather, but scare of hot weather, so I stopped the exercises. But I focus on taking caution of the dietary, why I cough before, I didn't have any cough that time, recently..seems seems there are some problem with the throat, I don't have the cough problem even when I was suffered from that pharyngolaryngitis.

[SL: Um um]

Chris: So I used mainly these two methods, I really tried my best, So, even though I am counting down now…my lung function counted down to 31, but I am still optimistic. [B364,438,GD]

Therefore, patients with severe illness conditions may have poorer HRQoL, if an educational intervention is given and their perceived self-efficacy improves, this may eventually mediate an improvement in their HRQoL. In my result, this improvement only happened in disease-specific HRQoL dimension and the overall mental aspects of generic HRQoL. This may imply that the effect of SMEP is limited to promote disease-affected well-being and at the same time merely serve as a psychological-and-mental support to general well-being of the participants. This point is supported by the following interaction from the focus group:

SL: Then what about Wilson? How do you feel about the follow-up telephone interview from Nurse MN

[Wilson: She she she]

SL: How was it?

Wilson: She sometimes called me from time to time and updated my situation, we do appreciate her consideration to us.

SL: Ar…is it helpful to your learning? I mean, would it strengthen or help remind you the knowledge that you have learnt? Any effects that help your learning?

Wilson: Yes yes, there were of course some effects, I mean followed her instruction and worked on it…to help keep my body well…more scientific.

SL: Ar…it means followed her instruction, what you mean is she could remind you? Right?

Wilson: Yes yes..

SL: It's not bad. What about Ivan? About this follow-up telephone interview…

Ivan: Follow-up telephone interview is quite good.

SL: also good..?

Ivan: I mean she cares for us. [A854-892,GD]

Apart from disease severity, pharmacological therapy may also have played an adverse role influencing the perception of illness, self-efficacy and HRQoL in this study. When the participant of this study was prescribed short-acting bronchodilator or/and they have increased the frequency of using short-acting bronchodilator, they were more likely to have a perception of having a chronic, cyclical and severe consequence of illness, and that also adversely affect their self-efficacy, disease-specific HRQoL and general physical aspects of generic HRQoL. This may be due to the fact that the higher the dose of medication the COPD patient received the more likely they were to have more severe illness condition or poorer pulmonary function which could affect his perception of psychosocial status as discussed earlier in this paragraph. Alternatively, this effect may be related to embedded negative impressions that the patient may hold towards pharmacological intervention. Leidy & Haase's (1996) study indicated that medications were often seen by the patients as adversely affecting mood, appearance, and activity levels. Treatments designed to help COPD patients may help symptomatically but may also indirectly cause adverse effects.

Interestingly, the symptom domain of SGRQ did not correlate with any demographic and clinical characteristics except the association with amount of smoking. A participant in the focus group highlighted this association:

Leon: Now it isn't, now…well now, sometimes there are phlegm when I smoke…it means cough with phlegm, then I..er…bought some liquid medicine, or that mycolytics that one called PoDaLing. [B183,223,12]

Smoking damages and eventually destroys cilia which become less effective at keeping the lungs clear, smokers may develop a habitual cough as they attempt to remove the mucus from their lungs (CDC, 2010). Thus, smokers have higher prevalence of respiratory symptoms (GOLD, 2013). The amount of smoking of the COPD patients in this study could probably have influence on level of the symptom-related QoL.

In summary, the severity of the illness state (for instance, clinical characteristics) and pharmacological intervention acted as the main roles in influencing the psychosocial aspects of COPD patients in Macau. Although we cannot reverse the COPD disease severity, we can help patients better understand their treatment regimen and enhance their self-efficacy in managing their disease condition through implementing SMEP. Their strong perception of self-efficacy may ultimately enable them to perceive better HRQoL, their disease-affected well-being and overall mental well-being in particular. One factor that would appear to be upmost importance in this study is that the SMEP might have delivered messages which enabled the participants to cope with their symptoms and that in turn helped to improve their HRQoL.

8.7 Conclusion

8.7.1 Significance of the Study

This study successfully employed the Medical Research Council framework in designing an exploratory trial for initiating a SMEP developed in the West to the Chinese population in Macau. SMEP was used to be in high variability and lack of uniformity in structure and content combination, hence, a SMEP was formulated by following the MRC framework for developing and evaluating complex intervention. A mix of quantitative approaches (objective clinical measures and validated questionnaires) and qualitative approach (focus groups) were adopted in an embedded design to reflect the subjective and objective outcomes of the study in the COPD patients in Macau. These outcomes confirmed the hypothesis that SMEP would appear to have a positive effect on COPD patients in Macau. This improvement was seen specifically in terms of enhancing inhaler technique, illness perception, self-efficacy and disease-specific domains of HRQoL, and reducing healthcare utilization. However, it did not have positive effect on their pulmonary function and generic HRQoL, consistent as reported in previous studies. Although, to date, COPD educational programme was not used widely in everyday clinical (Bucknall et al., 2012, Rootmensen et al., 2008), COPD patients in Macau emphasized the essentiality of such programme in the focus groups. This study has also identified the potential mediating effect of illness perception on self-efficacy in the formation of health behaviour in COPD patients. In addition, this study has made an attempt to identify the characteristics of patients who may benefit from the programme and support in self-management. Clinical characteristics (Stage of disease, post-BD FEV1% Pred., long-term treatment, prescribed MDI and frequency of using SABA) were shown to relate with their illness perception, self-efficacy and HRQoL. As defined in MRC guideline (2000), this study has obtained evidence for supporting the theoretically expected experimental effect, to identify appropriate outcome and estimates of recruitment required for a definitive RCT.

8.7.2 Implication for Nursing Application and Clinical Practice

Despite the overwhelming evidence that SMEP does not have a direct effect on improving pulmonary function and HRQoL in COPD, it has shown to improve patient engagement of appropriate medication management, to confront their condition with relevant illness perception, to manage their illness with better confidence and to reduce the number of days of hospitalization in Chinese COPD patients in Macau. These findings also suggest that the concept of self-management could be fostered within the programme through delivering cognitive information about the consequences and cyclical and chronic nature of COPD, to strengthen the patients' expectations and confidence in compliance to self-management initiatives (Kara and Aşti, 2004). It is of particular importance that SMEP, such as the one developed in this study, can be easily understood and implemented by clinical nursing personnel. Use of SMEP as such should not require a multidisciplinary effort which demands extra manpower or additional administrative costs. For those healthcare systems which have yet to introduce any form of chronic care to COPD patients, SMEP is recommended as an initiative approach for delivering continual care for this group of patients.

Nurses who conduct SMEP potentially play the roles of programme designer, coordinator, health educator, counsellor and consultant. A programme designer designs the structure and flow of the programme whilst the coordinator communicates with the institute administrators to gain support for running the programme and communicates with frontline doctors and nurses for referral of patients. Health educator delivers health-related information and skills to the participants for managing their illness. Counsellor provides emotional and mental support to the participants. Consultant helps to identify and solve difficult or hidden health problems of the participants. To gain the most benefits from SMEP, the findings of this study indicate that patients should be recruited to the programme before their condition has been developed into very severe stage of COPD. SMEP nurses could be more likely to foster self-management behaviour in these patients

through teaching proper inhaler technique and management of symptoms and exacerbations. In spite of the fact that the effectiveness of the action plan in a SMEP was inconclusive, it is still recommended as part of a standard self-management programme for COPD (Walters et al., 2010). Especially when a programme is multi-faceted or one which involves ongoing follow-up, it should allow repetition and practice in content delivery in order to assure continual engagement by the patients (Kaþýkçý, 2011). These approaches are recommended to design the structure and mode of chronic care delivery for COPD patients in Macau.

8.7.3 Limitations of the Study

This section identifies potential limitations in this study. These are mainly related to the potential bias underlying the research design and to the sampling structure. Although block randomization and blinding were adopted in the research design, the influence of participant preference may still be a potential confounder of true randomisation (MRC 2000). This could happen when the participants had a treatment preference, then they were likely to expect and achieve more positive outcomes; where relevant, compliance is likely to be improved. Participant preferences as such may result in bias which would limit the generalizability of results. Moreover, the favourable outcomes derived in the study may not purely be the results of the SMEP itself. They may also be due to the participant preference to the researcher or the halo effect. The halo effect is generally defined as the influence of a global evaluation of individual attributes of a person simply by colouring interpretation of the meaning or affective value of individual trait (Nisbett and Wilson, 1977). This should be especially taken into consideration as traditional Chinese culture upholds helping members of communal relationships. They help through manifesting appreciation as a response of role requirements and maintaining social relationship (Hwang, 2012). However, it is very difficult to avoid this type of bias in this type of study, as the researcher held a compulsory role for conducting and implementing the complex intervention. Another external factor which could potentially interfere with the effect of the SMEP could be peer influence or the use of alternative therapies voluntarily adopted by the participants during the research process. For example, a CG

participant reported that they took herbs and animal soup and a participant in SMG has received a course of herb application to acupuncture points. On the other hand, recruitment of participants from Health Bureau was rejected as my sample has excluded COPD patients who solely rely on public healthcare service. Additionally, this may have hindered the recruitment of larger sample and inhibited the formation of a third group, the placebo group, which would have controlled for the halo effect in the study. The limited sample size also made impossible to run statistical tests of minimal clinical significance for the primary end outcomes. Despite these limitations, this study did employ possible measures to ensure rigor in the research process and obtain outcomes confirming the hypothesis.

8.7.4 Directions for Future Research

Quantitative and qualitative approaches in this study show that COPD patients in Macau did derive benefit from SMEP. This supports the proposed theoretical framework of this study and provides the foundation for a larger RCT. On top of that, other forms of measurement, analysis methods, research design possible for answering further research questions have been identified during the time of the study. First, direct observation of self-management behaviour through objective measures have been recommended in a very recent study. It has indicated that only 42% of intervention group patients learnt to self manage and that was expected to act as a threshold of improving other biomedical and psychosocial outcomes (Bucknall et al., 2012). Moreover, a newly validated disease specific HRQoL named COPD Assessment Test (CAT) was developed whilst this study was being conducted. CAT is an eight-question quality of life instrument assessing the impact of symptoms in COPD. It was strongly correlated with SGRQ and hence can be considered to replace the more time-consuming SGRQ in further COPD research studies (Jones et al., 2011). This study has indicated the potential mediating role of illness perception belief in self-efficacy in COPD patients. However, further investigation of illness perception belief-driven intervention and its predictive role through multivariate analysis is recommended. Understanding of this may help clinicians to better incorporate illness perception belief into the SMEP to enhance the self-efficacy for self-management efficiently and effectively in COPD patients. In order to minimize

placebo effect and differentiate the actual effect of SMEP from potential placebo effect, three groups which comprise one interventional group, one control group and one placebo group are suggested to the study design. Furthermore, evaluation of the implementation process of the SMEP is advised. This would provide a check of whether the planned improvement activities had been executed uniformly and whether the target population has actually been exposed to activities as planned (Lemmens et al., 2008). If SMEP has been run maturely as well as a growth of multidisciplinary cooperation in the healthcare system, further studies for exploring the effects of a self-management integrated chronic care model are recommended to Chinese COPD patients.

8.8 Summary

To date, there has been no scientific investigation of COPD care delivery to Chinese patients in Macau. In this study, examination of the effect of a self-management education programme on these patients was conducted and the role of both beliefs of illness perception and self-efficacy in their engagement to self-management was critically explored. This knowledge will contribute to improve the understanding of how Macau Chinese COPD patients benefited from self-management intervention. It also provides insight into the perception of these patients towards SMEP. However, it should be noted that the current findings were obtained from an exploratory trial which has affirmed the modelling of the study framework. This should be acknowledged in overall generalization of the effectiveness of SMEP in Chinese COPD patients. On the contrary, this study also provides important information and experiences for the development of similar SMEP in other chronic illness (for instance, diabetes, hypertension, coronary heart disease) in South East Asia.

SMEP is not intended as a curative intervention. It does not aim to reverse the deteriorating pulmonary function and generic HRQoL of COPD patients. In this study, when the patients' COPD deteriorated and they became more dependent on pharmaceutical therapy, they tended to perceive worse consequences of their illness and display weaker self-efficacy to manage their condition. However, SMEP managed to alter their perceptions with a realistic timeline and maintain their declining personal control of COPD. Also, SMEP helped to enhance various dimensions of self-efficacy and that may in turn improve the HRQoL, particularly limited to the disease-affected well-being and overall mental well-being of COPD patients. Echoing by the qualitative findings, the essentiality of SMEP was affirmed among these Chinese COPD patients, while its limitation in reversing the progressive nature of the disease was also stressed. Preliminary evidence for the relationship between illness perception belief and self-efficacy belief in mediating health behaviour was initially indicated in COPD patients in this study and this provides a foundation for developing and examining further cognitive-behavioural

beliefs-integrated intervention on this population. To actualize COPD self-management, it is not only important to develop an effective and cultural applicable intervention, a mutual involvement from national level to individual level of stakeholders in paying concern and effort in promotion and implementation of self-management is prominently indicated. Thus, this study highlighted that Macau Chinese COPD patients demonstrated readiness to receive self-management intervention and they derived benefits from it. In conclusion, SMEP can serve as an acceptable and preferable mode of chronic care for COPD for the healthcare system of Macau.

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Appendix

Appendix 1 Brief Introduction to Macau

Geographical characteristics

The Macau Special Administrative Region (Macau SAR) is one of the two special administrative regions of the People's Republic of China, the other one is Hong Kong. Macau, which had been the colony of Portugal for over 400 years was handover to China in 1999 and is currently ruled under the policy of "One country, two systems". Macau is located in Guangdong province, on the western bank of the Pearl River Delta (MGOT, 2013). Macau has an area of 29.9 km^2, comprised of the Macau Peninsula and connected to Mainland China, the islands of Taipa and Coloane. According to the data of the Statistics and Census Service in Macau (DSEC) (2012), the population of Macau is estimated to be 582,000. Therefore, Macau is one of the most densely populated region in the world, with population density of around 19,465 persons per km^2 (DSEC, 2012). The ethnic distribution of its population is 94.3% Chinese and the remainder is of Portuguese or mixed Chinese-Portuguese ancestry. The Per-capita Gross Domestic Product (GDP) at current price was MOP 531,723 which is equivalent to approximately £45,838400 (DSEC, 2012).

Healthcare System

According to Government Information Bureau (2012), the healthcare delivery of Macau is mainly served by the public sector "Health Bureau" , and two private hospitals and one day hospital, namely Kiang Wu Hospital (established for 142 years) and Macau University of Science and Technology Hospital (established for seven years), and MALO Clinic Health and Wellness (established for less than two years). There were 379 private clinics running by general practitioners in which 243 clinics providing Traditional Chinese Medical (TCM) therapy and care (GCS, 2012). The Health Bureau runs a public hospital, the Conde S. Januário Hospital Centre (CHCSJ) (established for more than 130 years), six health centers, two health stations and the Center for Disease Control and Prevention, providing specialized and primary health care to the public in Macau (SSM, 2012a). The number of accumulated hospital bed of all the three hospitals Macau is around 1,300, with CHCSJ and Kiang Wu Hospital each sharing about 45% of them (GCS, 2012, KWH, 2008). Currently, none of the Macau hospitals is independently assessed through international healthcare accreditation. There are no western-style medical schools in Macau and all aspiring physicians receive their medical education elsewhere. Meanwhile, there are two nursing educational institutes, the Kiang Wu Nursing College of Macau and Macau Polytechnic Institute, both have ever been training local nurses for Macau. In regard to the demographic data of the healthcare professionals, there were only 2.6 doctors and 2.9 nurses for every thousand population of Macau in (DSEC, 2012). These figures were much lower than that in UK which was 2.7 and 10.1 for every thousand population for doctors and nurses respectively (WHO, 2012).

Health-related Policy

The Health Bureau provides acute, rehabilitative, in and out-patient care and primary care to the public. In particular, the primary health care net spread on different districts of the community providing free primary health care services to the residents of Macau (SSM, 2012a). In addition, the Health Bureau also covers the healthcare expenses of the following residents of Macau in terms of law:

- Pregnant, parturient, puerperal patients (until the end of the first month after birth), (present the identity document);
- Children until ten years-old (present the identity document);
- Students of primary and secondary schools (present the Student Card issued by the Department of Education and Youth);
- Indigents (present a valid Certificate of Indigence issued by the Macau Social Welfare Department);
- Persons over 65 years-old (present the identity document);
- Cancerous patients, the mentally-handicapped, carriers of infectious-contagious diseases and drug-addicts (present the respective Access Card to Health Care, which is issued by presentation of Medical Certificate);
- Access Card to Health Care holders, those card must be issued by Social Work Service of the Department of Health, Macau SAR;
- Users who are Macau Resident Identity Card holders and have access to the Health Centres.

Macau residents who neither require primary healthcare service nor fulfill the above criterion, have to pay for the healthcare at their own expenses. Also, the Health Bureau is mainly responsible for coordinating the activities between the public and private organizations in the area of public health, setting public health guidelines for hospitals and private health care providers, but by no means regulating the quality of healthcare service and professionals.

Appendix 2 Ethical Approval from the University of Edinburgh

The University of Edinburgh
College of Humanities and Social Science

SCHOOL OF HEALTH IN SOCIAL SCIENCE

APPROVAL BY SUBJECT AREA RESEARCH ETHICS TEAM/ CO-ORDINATOR (LEVEL 2)

Name/s of Researcher/s:	Wai I Ng
Proposed Title of Research:	An exploratory trial for examining effects of self-management education on patients with chronic obstructive pulmonary disease in Macau
Funding Body (if appropriate):	Self funded
General Comments:	
Outcome: (please tick box)	**Approved** ☑ **Approved with Conditions (see attached)** ☐ **Not Approved** ☐
If approved with conditions, name of person to oversee these:	

The above research proposal has been approved by the subject area research ethics team/co-ordinator.

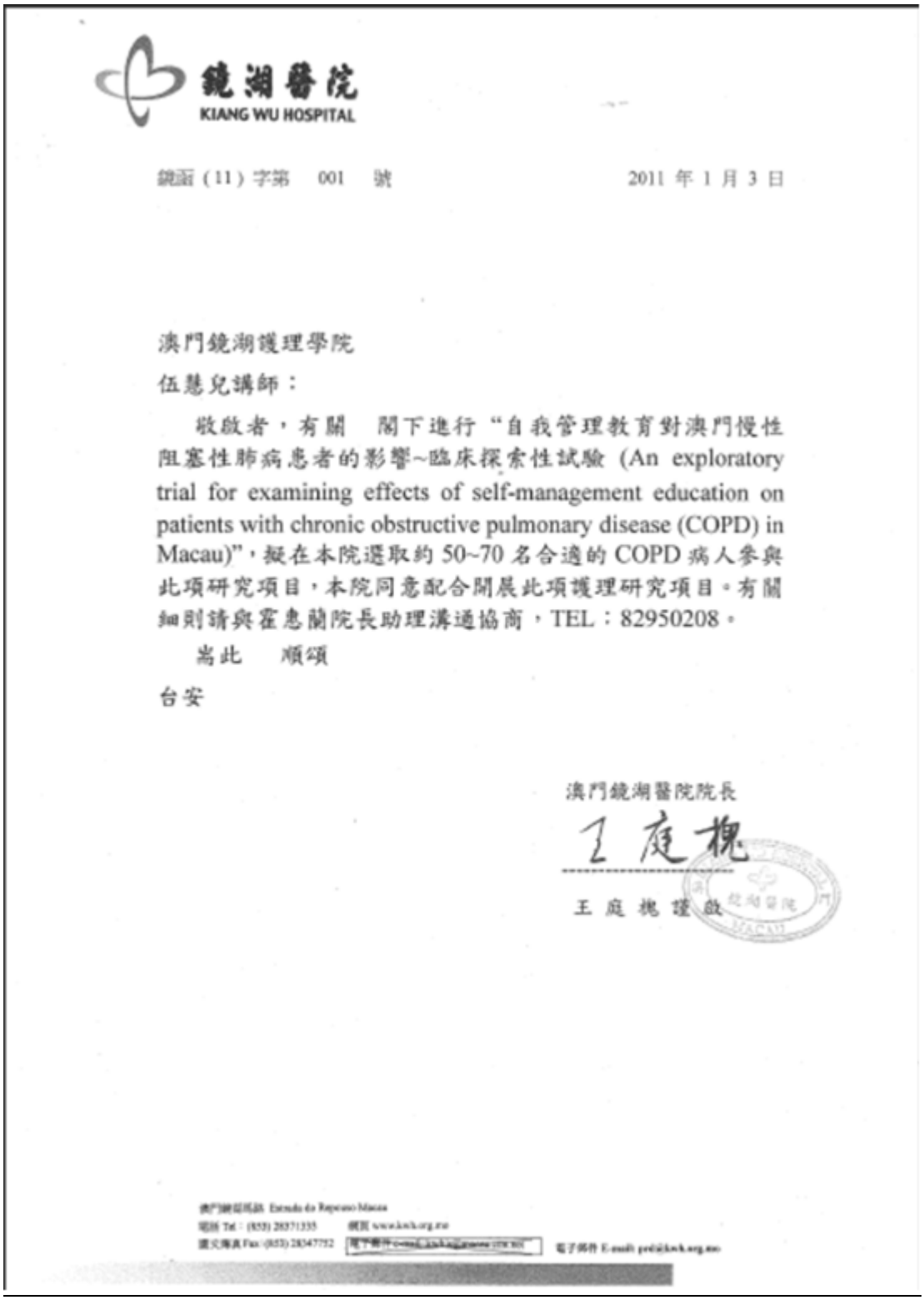
Signed: ..... *(Professor Kath Mella)*

Date: ..... 20-1-11 .....

Signed: ..... *(name of person)*

Date: .....

Appendix 3 Hospital approval [No.(11)001]



鏡湖醫院
KIANG WU HOSPITAL

鏡函（11）字第 001 號 2011 年 1 月 3 日

澳門鏡湖護理學院

伍慧兒講師：

敬啟者，有關 閣下進行“自我管理教育對澳門慢性阻塞性肺病患者的影響~臨床探索性試驗 (An exploratory trial for examining effects of self-management education on patients with chronic obstructive pulmonary disease (COPD) in Macau)”，擬在本院選取約 50~70 名合適的 COPD 病人參與此項研究項目，本院同意配合開展此項護理研究項目。有關細則請與霍惠蘭院長助理溝通協商，TEL：82950208。

耑此 順頌

台安

澳門鏡湖醫院院長

王庭槐

王庭槐謹啟

澳門鏡湖馬路 Estrada do Repouso Macau
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Appendix 4 Study Information Sheet for Experimental group participants

Study Information Sheet (No. E1)

Study Title : An exploratory trial for examining effects of self-Management education programme on patients with chronic obstructive pulmonary disease (COPD) in Macau

You are cordially invited to take part in a research study which is carried out by NG Wai I, a doctoral student of University of Edinburgh and a lecturer of Kiang Wu Nursing College of Macau. The study is officially approved for implementation here by Kiang Wu Hospital.

Aims of the Study

This study is to examine the effects of self-management education and to identify the elements of nursing care that are most suitable to the patients with COPD in Macau. The findings obtained from this study may probably help to construct a more effective and appropriate local care delivery mode for COPD and to provide a framework for developing a nursing care model for chronically ill of Chinese population in Macau.

Why are you chosen?

This is a study which is particularly exploring the self-managing experiences and better care delivery for COPD patients in Macau. You are one of this target patient group who can provide help and contribute to this work. Your taking part means a lot to the improvement of COPD care and to my doctoral study.

How will the study be carried out?

Consented participants may be invited to attend a programme which consists of three 1.5 –hour workshops given by experienced respiratory educator or nurse. Participants have to fill in some questionnaires before and after the programme and this will take around 30 minutes. Some may have to attend a group audio-recorded interview six months after the programme and the interview may last 45 to 60 minutes. The physician visit and service to the participants would be as usual in the due course.

Is it compulsory to take part?

Taking part is completely voluntary; you are not obliged to take part. You are free to withdraw at any time during the process without any adverse treatment.

What will happen if I want to take part?

If you decide to take part in this study, you will be given a pulmonary function test. If you are eligible, you will be asked to sign a consent form. You will be told when and where you will attend the workshops. The workshops will be about information of

COPD and the ways of managing this disease through oral-teaching, demonstration and re-demonstration. The workshops will be held in the out-patient department of Kiang Wu Hospital. The information you provide in questionnaires and interviews will be kept confidential to ensure anonymous. The data will be discarded 3 year after the whole study is deemed completed.

Can you know about the results of the study?
If you want to know about the results of yourself, you can be feedback the results of your assessments done in the study.

If you have any query or complaints about the study throughout the process, please feel free to contact the following persons.

Researcher Contact Details

Milly Wai I NG
PhD Student in Nursing Studies
University of Edinburgh

Tel No: XXXXXXXXX
Email : XXXXXXXX@sms.ed.ac.uk

Alternative Contact Details

Dr. Graeme D Smith
Senior Lecturer
Medical School, Teviot Place
School of Health in Social Science
University of Edinburgh
Tel No: XXXXXXXX
Email : XXXXXXXX@ed.ac.uk

Thank you very much for your concern and support to the development of nursing care for COPD patients!!

Appendix 5 Informed consent form for experimental group participants

Informed Consent Form

An exploratory trial for examining effects of self-Management education programme on patients with chronic obstructive pulmonary disease in Macau

Consent to participation

1) I have read and understood the study information sheet (No. E1) for the above project and have been clarified doubts and questions. ☐

2) I understand the potential risk for participating in the study and I have right to withdraw from the study at any time without any adverse effects ☐

3) I understand that all information taken by the researchers during the process of the study will be treated confidentially and will be anonymised. ☐

4) I understand that the data collected will be carefully destroyed three year after the study is completed. ☐

5) I agree that I am randomly allocated to self-management education programme. ☐

6) I understand that the study will last nine months, and I agree to provide data through questionnaires and audio-recorded group interviews. ☐

7. I agree to participate in the study. ☐

_____	_____	_____
Participant name (Print)	Date	Signature
_____	_____	_____
Researcher name (Print)	Date	Signature

Appendix 6 Study Information Sheet for control group participants

Study Information Sheet (No. C1)

An exploratory trial for examining effects of self-Management education programme on patients with chronic obstructive pulmonary disease (COPD) in Macau

You are cordially invited to take part in a research study which is carried out by NG Wai I, a doctoral student of University of Edinburgh and a lecturer of Kiang Wu Nursing College of Macau. The study is officially approved for implementation here by Kiang Wu Hospital.

Aims of the Study

This study is to examine the effects of self-management education and to identify the elements of nursing care that are most suitable to the patients with COPD in Macau. The findings obtained from this study may probably help to construct a more effective and appropriate local care delivery mode for COPD and to provide a framework for developing a nursing care model for chronically ill of Chinese population in Macau.

Why are you chosen?

This is a study which is particularly exploring the self-managing experiences and better care delivery for COPD patients in Macau. You are one of this target patient group who can provide help and contribute to this work. Your taking part means a lot to the improvement of COPD care and to my doctoral study.

How will the study be carried out?

Consented participants would be invited to be under monitor for 9 months. During this period, participants have to fill in some questionnaires at two time points and this will take around 30 minutes for each time. Some may have to attend a group audio-recorded interview and the interview may last 45 to 60 minutes. The physician visit and service to the participants would be as usual in the due course.

Is it compulsory to take part?

Taking part is completely voluntary; you are not obliged to take part. You are free to withdraw at any time during the process without any adverse treatment.

What will happen if I want to take part?

If you decide to take part in this study, you will be given a pulmonary function test. If you are eligible, you will be asked to sign a consent form. Then, you will be arranged to be interviewed at your best convenience. During the 9 months monitoring, researcher will call you regularly to update your condition. The information you provide in questionnaires and interviews will be kept confidential to ensure anonymous. The data will be discarded 3 year after the whole study is deemed

completed.

Can you know about the results of the study?
If you want to know about the results of yourself, you can be feedback the results of your assessments done in the study.

If you have any query or complaints about the study throughout the process, please feel free to contact the following persons.

Researcher Contact Details

Milly Wai I NG
PhD Student in Nursing Studies
University of Edinburgh

Tel No: XXXXXXXX
Email : XXXXXXXX@sms.ed.ac.uk

Alternative Contact Details

Dr. Graeme D Smith
Senior Lecturer
Medical School, Teviot Place
School of Health in Social Science
University of Edinburgh
Tel No: XXXXXXXX
Email : XXXXXXXX@ed.ac.uk

Thank you very much for your concern and support to the development of nursing care for COPD patients!!

Appendix 7 Informed consent form for experimental group participants

Informed Consent Form

An exploratory trial for examining effects of self-Management education programme on patients with chronic obstructive pulmonary disease in Macau

Consent to participation

1) I have read and understood the study information sheet (No. C1) for the above project and have been clarified doubts and questions. ☐

2) I understand the potential risk for participating in the study and I have right to withdraw from the study at any time without any adverse effects ☐

3) I understand that all information taken by the researchers during the process of the study will be treated confidentially and will be anonymised. ☐

4) I understand that the data collected will be carefully destroyed three year after the study is completed. ☐

5) I agree that I am randomly allocated to be under monitoring. ☐

6) I understand that the study will last nine months, and I agree to provide data through questionnaires and audio-recorded group interviews. ☐

7. I agree to participate in the study. ☐

_____	_____	_____
Participant name (Print)	Date	Signature
_____	_____	_____
Researcher name (Print)	Date	Signature

Appendix 8　Questionnaire for Pre- and Post-assessment

自我管理教育對澳門慢性阻塞性肺病(COPD)患者的影響 ~ 臨床探索性實驗

您好! 感謝您同意參與這個名為『自我管理教育對澳門慢性阻塞性肺病(COPD)患者的影響 ~ 臨床探索性實驗』的研究項目。以下是問卷填寫，問卷分為兩個部份：第一部份是個人基本資料，第二部份是與患病相關的問題。請根據您的個人情況如實作答便可，調查員會協助您完成。在此，再次感謝您的參與!

參與者編號：_____
調查員編號：_____
調查日期 ：_____ (Pre / Post)

請在相應選項上**打(√)**

1. 性　　別：(1)男 / (2) 女　　X1. ☐

2. 年　　齡：_____　　X2. ☐☐

3. 醫生診斷：(1)肺氣腫 / (2)慢性支氣管炎 / (3)COPD (*可多選*)　　X3a. ☐
　　X3b. ☐
　患病年數：_____ (最長患病年數)　　X3c. ☐

4. **肺功能測定**　　X4a . X4b .
　FEV1：Pre-BD _____ (_____% Pred.)　　☐☐
　Post-BD_____ (_____% Pred.)　　X4c ☐ X4d ☐
　Post-BD FEV1 / FVC _____　　X4e. ☐
　COPD 分期：(1) Stage I / (2) Stage II / (3) Stage III / (4) Stage IV　　X4f. ☐

5. 其它慢病診斷：(0)沒有 / (1)心血管系統 / (2)神經系統 /　　X5a. ☐
　(3)骨骼肌肉系統 / (4)內分泌系統 /　　X5b. ☐
　(5)泌尿系統 / (6)消化系統 /　　X5c. ☐
　(7)其它 _____ (*可多選*)　　X5d. ☐

6. 工作情況：(0)退休 / (1)就業 / (2)失業 / (3)因病喪失工作能力 /
　(4)其它_____　　X6. ☐

7. 居住狀況：(0)獨居 / (1)與妻子同住 / (2)與伴侶及子女同住 /
　(3)與親朋同住 / (4)其它_____　　X7. ☐

8. 婚姻情況：(0)未婚 / (1)已婚 / (2)離婚 / (3)鰥寡 / (4)同居　　X8. ☐

9. 疾病開支：(0)政府支助 / (1)自付 / (2)家人付 / (3)保險 /
(4)慈善支助 / (5)其它 _____ (可多選) X9a. ☐ X9b. ☐

10. 吸煙情況：(0)不吸煙 (1) 吸煙 _____pack year (包數 x 總年數) X10a. ☐ X10b ☐
(2) 戒煙

X11. 教育程度 : (0) 沒有接受過教育 (1) 小學程度 X11 ☐
(2) 中學程度 (3) 大學或學位後教育

疾病及治療情況

11. 你正長期使用哪些呼吸科藥物? (*可多選)*	(0) 沒有 (1) 短效支氣管擴張劑 (2) 混合支氣管舒張劑 (3) 長效支氣管舒張劑 (4) 混合性預防劑 (5) 預防性激素(吸入) (6) 口服激素 (7) 口服支氣管舒張藥 (8) 靜脈注射激素	X11a. ☐ X11b. ☐ X11c. ☐ X11d. ☐
12. 你有否使用儲霧器?	(0)沒有 (1)有 (2)不適用	X12. ☐
13. 過去 6 個月有否因氣促或喘氣而使用短效支氣管擴張劑?	(0)沒有 (1)平均每週 1~2 次 (2)平均每週>2 次, <7 次 (3)平均每天 1 次 (4)平均每天>1 次	X13. ☐
14. 過去 6 月有否因氣促、咳嗽加重而求醫(門診/急診，非劃性)?	(0)沒有 (1)有 (_____次)	X14a. ☐ X14b. ☐
15. 過去 6 個月有因呼吸道疾患而住院?	(0) 沒有 (1) 有 (____次，合共_____天)	X15a. ☐ X15b. ☐ X15c. ☐
16. 過去 6 個月有否接受流感/肺炎鏈球菌疫苗接種?	(0)沒有 (1)有	X16. ☐

聖 佐 治 胸 肺 科 問 卷 (SGRQ)

這份問卷設計的目的在於了解更多你的氣喘情況 / 毛病 / 問題及它如何影響你的生活，藉以找出你最大的問題。

甲部

請於每題中選出一個最適當的答案，並(√)。

	每星期差不多每天	每星期有多天	每星期有幾天	每當肺部受感染	甚少	
一. 於過去四星期內，我咳嗽的頻密程度是：	❑	❑	❑	❑	❑	B1. ____
二. 於過去四星期內，我有痰的日子是：	❑	❑	❑	❑	❑	B2. ____
三. 於過去四星期內，我感到呼吸困難的次數：	❑	❑	❑	❑	❑	B3. ____
四. 於過去四星期內，我遇上「牽哈」的日子：	❑	❑	❑	❑	❑	B4. ____

五. 於過去四星期內，你有多少次嚴重的胸肺病發作？
超過三次❑ 三次❑ 二次❑ 一次❑ 沒有❑ B5. ____

六. 最嚴重的一次胸肺病發維持了多久？
(若題五選擇答案 '沒有' ，不用作答此題)
一星期或以上❑ 三天或以上❑ 一至兩天❑ 少於一天❑ 不適用❑ B6. ____

七. 於過去四星期內每星期你平均有多少天沒有被胸肺問題困擾？
沒有❑ 一至兩天❑ 三至四天❑ 幾乎每天❑ 每天❑ B7. ____

八. 若遇有「牽哈」時，是否在朝早較為嚴重？
不是❑ 是❑ B8. ____

乙部

(一) 你會怎樣形容你的胸肺情況？

- 是我最要緊的問題 ----------❑
- 給我構成甚多問題 ----------❑
- 給我構成一些問題 ----------❑
- 沒有構成問題 ---------- ❑ B9. ____

若你曾有受薪工作，請在以下✓最適當的答案。

- 我的胸肺問題令我要停止工作 ---------- ❑
- 我的胸肺問題影響我的工作或令我要轉換工作 ---- ❑
- 我的胸肺問題不影響我的工作 ---------- ❑ B10. ____

(二) 在近期有甚麼活動常導致你感到氣喘。

	是	否	
• 坐或躺臥 ----------	❑	❑	B11. ____
• 梳洗或更衣 ----------	❑	❑	B12. ____
• 在家中步行 ----------	❑	❑	B13. ____
• 在戶外走平路 ----------	❑	❑	B14. ____
• 上一層樓梯 ----------	❑	❑	B15. ____
• 行山 ----------	❑	❑	B16. ____
• 做運動或比賽 ----------	❑	❑	B17. ____

(三) 以下問題是關於近期咳嗽和氣喘的情況。

	是	否	
• 我的咳嗽令我感到不適 ----------	❑	❑	B18. ____
• 我的咳嗽令我感到疲倦 ----------	❑	❑	B19. ____
• 說話時，我感到透不過氣來 ----------	❑	❑	B20. ____
• 彎腰時，我感到透不過氣來 ----------	❑	❑	B21. ____
• 我的咳嗽或呼吸問題影響我的睡眠 ----------	❑	❑	B22. ____
• 我容易感到精力耗盡 ---------- ❑ ❑			B23. ____

(四) 以下問題是關於近期你的胸肺問題對你構成的其他影響。

	是	否	
• 在公眾場合中，我的咳嗽或呼吸問題令我感到尷尬 ----------	❑	❑	B24. ____
• 我的胸肺問題令家人，朋友及鄰居感到討厭---	❑	❑	B25. ____
• 當我不能控制呼吸時，我便會驚惶失措---------	❑	❑	B26. ____
• 我覺得不能控制自己的胸肺問題 ----------	❑	❑	B27. ____
• 我不期望自己的胸肺情況會好轉 ----------	❑	❑	B28. ____
• 我因自己的胸問題而變得脆弱或無用 ----------	❑	❑	B29. ____

• 運動對我來說是不安全的 ----------❑	❑	B30.	
• 一切對於我來說都感到吃力 ----------❑	❑	B31.	

(五) 以下問題是關於藥物治療的情況。
(若你沒有使用藥物治療，請跳去第六節)

	是	否		
• 我的藥物對我幫助不大 ----------❑	❑		B32.	
• 在公眾場所用藥令我感到尷尬 ----------❑	❑		B33.	
• 我對所用的藥物有不良的副作用 ----------❑	❑		B34.	
• 我的藥物對我的生活造成很多干擾 ----------❑	❑		B35.	

(六) 以下問題是關於你的活動如何被你的呼吸問題困擾。

	是	否		
• 我梳洗或更衣需時良久 ----------❑	❑		B36.	
• 我不能洗澡或淋浴，或需時良久 ----------❑	❑		B37.	
• 我步行較其他人慢，或需要中途休息 ----------❑	❑		B38.	
• 工作時，例如料理家務，需時良久或 要中途休息 ----------❑	❑		B39.	
• 若我要上一層樓梯，也要慢慢步上或停下來--❑	❑		B40.	
• 若我趕急或快步走路，也要停下來或慢下來--❑	❑		B41.	
• 我的呼吸問題令我難做到，例如： 行山，挽東西上樓梯，輕便的園藝如除草， 跳舞，打保齡球或打高爾夫球等 ----------❑	❑		B42.	
• 我的呼吸問題令我難做到，例如： 挽重物，在花園翻泥土或鏟雪，緩步跑或以每 小時五英里的速度步行，打網球或游泳等 -----❑	❑		B43.	
• 我的呼吸問題令我難做到，例如： 十分粗重的工作，跑步，踏單車，快速 地游泳或進行比賽性的運動 ----------❑	❑		B44.	

(七) 以下問題目的是想知道你的胸肺問題如何影響你的日常生活。
(註：因呼吸問題導致你不能做某些事才在「是」打**(√)**

	是	否		
• 令我不能做運動或比賽 ----------❑	❑		B45.	
• 令我不能外出消遣或娛樂 ----------❑	❑		B46.	
• 令我不能外出購物 ----------❑	❑		B47.	
• 令我不能做家務 ----------❑	❑		B48.	
• 令我不能走動離開我的床或椅子太遠 ----------❑	❑		B49.	

下有一系列其他活動可能因你的胸肺問題令你做不到。
(你不用在每項中作出回應，它們純屬例子，目的只在於提醒你怎樣被呼吸問題影響自己)。

例：
- 外出散步或拖狗
- 在家中作事或園中工作
- 行房
- 外出消遣，去教堂或去娛樂場所
- 在天氣差的日子出外或進入煙霧瀰漫的房間
- 探訪親友或和小孩子玩耍

OQ1. 請在下面填上其他因你的胸肺問題導致你做不到的重要活動：

_____

_____

_____

_____

_____

請在以下選出一項答案最能描述胸肺問題對你的影響：

- 它不阻礙我做任何我喜歡做的事 ---------- ❑
- 它阻礙我做一至兩件我喜歡做的事 ---------- ❑
- 它阻礙我做很多我喜歡做的事 ---------- ❑
- 它阻礙我做一切我喜歡做的事 ---------- ❑ B50. ☐

(Direct translated from The St. George’ s Respiratory Questionnaire P.W. Jones , F.H. Quirk and .M.Baveystock.)

慢性阻塞性肺疾病自我效能量表 (CSES)

填表說明：閱讀以下列舉的項目，并决定在這些情况下，您有多大的信心去應付或避免呼吸困難。請按如下尺度作答：

(1) = 非常有信心
(2) = 相當有信心
(3) = 有少許信心
(4) = 無信心
(5) = 非常無信心

請打相應數字上打 (√)

	非常有信心 (1)	相當有信心 (2)	有少許信心 (3)	無信心 (4)	非常無信心 (5)	
1. 當我感到太累時。	1	2	3	4	5	C1. ☐
2. 當四周的空氣潮濕時。	1	2	3	4	5	C2. ☐
3. 當我從溫暖的環境，進入寒冷的環境時。	1	2	3	4	5	C3. ☐
4. 當我覺得情緒緊張或不開心時。	1	2	3	4	5	C4. ☐
5. 當我上樓梯上得太快時。	1	2	3	4	5	C5. ☐
6. 當我否認我有呼吸困難時。	1	2	3	4	5	C6. ☐
7. 當我周圍都有香煙的煙霧時。	1	2	3	4	5	C7. ☐
8. 當我生氣時。	1	2	3	4	5	C8. ☐
9. 當我運動或付出很大的體力時。	1	2	3	4	5	C9. ☐
10. 當我爲我的生活而感到苦惱時。	1	2	3	4	5	C10. ☐
11. 當我感到性交不足或不舉時。	1	2	3	4	5	C11. ☐

	非常有信心 (1)	相當有信心 (2)	有少許信心 (3)	無信心 (4)	非常無信心 (5)	
12. 當我感到無奈時。	1	2	3	4	5	C12.
13. 當我舉起重的物件時。	1	2	3	4	5	C13.
14. 當我大叫或大聲說話時。	1	2	3	4	5	C14.
15. 當我躺床上休息時。	1	2	3	4	5	C15.
16. 在非常炎熱或寒冷的天氣裏。	1	2	3	4	5	C16.
17. 當我笑得很多時。	1	2	3	4	5	C17.
18. 當我沒有跟隨適當的日常飲食時。	1	2	3	4	5	C18.
19. 當我感到無助時。	1	2	3	4	5	C19.
20. 當我受到感染(如：喉嚨、鼻竇感染，傷風感冒等)時。	1	2	3	4	5	C20.
21. 當我感到孤立而不想理會所有人或所有事時。	1	2	3	4	5	C21.
22. 當我覺得焦慮時。	1	2	3	4	5	C22.
23. 當我在污染的環境中。	1	2	3	4	5	C23.
24. 當我吃得過多時。	1	2	3	4	5	C24.
25. 當我感到沮喪或意志消沉時。	1	2	3	4	5	C25.
26. 當我在空氣不流通的房間運動時。	1	2	3	4	5	C26.
27. 當我害怕時。	1	2	3	4	5	C27.
28. 當我經歷到失去重要的物件或摯愛時。	1	2	3	4	5	C28.
29. 當我家中有問題時。	1	2	3	4	5	C29.
30. 當我感到不能勝任時。	1	2	3	4	5	C30.

31. 當我匆忙時。	1	2	3	4	5	C31.

疾 病 感 知 問 卷 (IPQ-R)

您本人對患病的看法及觀感

以下是在一般患病過程中，可能會出現的症狀，有些症狀您可能經歷過，有些則或許您從來也沒經歷過。為了增進我們的了解，我們希望您能根據您的情況，圈出，第一，**您是否有過以下症狀**；第二，您認為您的症狀**與您目前所患的疾病是否有關**。

請在’有’或’無’上打 (√)

在患病後 我有(無)此症狀				此症狀和我目前的病有(無)關			
	(1)	(0)		(1)	(0)		
疼痛	有	無	_____	有	無	D1a.	D1b.
喉嚨痛	有	無	_____	有	無	D2a.	D2b.
噁心作嘔	有	無	_____	有	無	D3a.	D3b.
呼吸困難	有	無	_____	有	無	D4a.	D4b.
體重減輕	有	無	_____	有	無	D5a.	D5b.
疲倦	有	無	_____	有	無	D6a.	D6b.
關節僵硬	有	無	_____	有	無	D7a.	D7b.
眼痛	有	無	_____	有	無	D8a.	D8b.
頭痛	有	無	_____	有	無	D9a.	D9b.
胃部不適	有	無	_____	有	無	D10a.	D10b.
睡眠問題	有	無	_____	有	無	D11a.	D11b.
頭暈	有	無	_____	有	無	D12a.	D12b.
全身乏力	有	無	_____	有	無	D13a.	D13b.

除了您的症狀以外，我們也希望能了解，您個人**對目前病情的看法**。

以下問題，請在符合您想法的空格內打**(√)**。

我認為我的病…..	完全不同意	不同意	沒意見	同意	非常同意	
IP1* 將在短時間內痊癒						IP1.
IP2 是永久性而非短時間的						IP2.
IP3 會拖很長一段時間						IP3.
IP4* 應該很快就會好了						IP4.

IP5 會跟著我一輩子，永遠好不了						IP5.
IP6 情況非常嚴重						IP6.
我認為我的病…..	完全不同意	不同意	沒意見	同意	非常同意	
IP7 對我的一生，帶來嚴重的後果						IP7.
IP8* 對我的人生沒什麼大影響						IP8.
IP9 嚴重影響到別人對我的看法						IP9.
IP10 為我帶來十分沉重的經濟負擔						IP10.
IP11 對我身邊的 人帶來很多困難						IP11.
IP12 應該有很多方法可以控制住我的症狀						IP12.
IP13 我的病情的好壞，決定於我個人所作所為						IP13.
IP14 我的個人因素，可以改變整個患病的過程						IP14.
IP15* 無論我怎麼做都影響不了我的病						IP15.
IP16 我認為我有力量可以改變我的病						IP16.
IP17* 不管怎麼做，最終對我的病，都沒什麼幫助						IP17.
IP18* 病情將會隨著時間而有所改善						IP18.
IP19* 要改善眼前病情，實在所能做的十分有限						IP19.
IP20 目前的治療方法，會有效的治好我的病						IP20.
IP21 目前治療方法，可以預防或避免因疾病造成的不良後果						IP21.
IP22 目前的治療方法，可以控制住我的疾病						IP22.
IP23* 已經是再也沒什辦法，可以改善我的情況了						IP23.
IP24 有很多症狀讓我很不解						IP24.
IP25 對我來說跟謎一樣,十分神秘						IP25.
IP26 對我來說，我是一點概念也沒有						IP26.
IP27 我實在無法理解我的病						IP27.
IP28* 所有的病情及變化，我都很了解						IP28.
IP29 病況變化很大，似乎每天都有所不同						IP29.

我認為我的病…..	完全不同意	不同意	沒意見	同意	非常同意	
IP30 症狀總是反反覆覆、來來去去的						IP30.
IP31 完全沒法子預測						IP31.
IP32 我已經歷了多次來來回回、好好壞壞的病情						IP32.
IP33 事實上只要一想到病，我就感到很憂鬱						IP33.
IP34 每當想到我的病時，我就感到很沮喪						IP34.
IP35 我對自己得這個病非常生氣						IP35.
IP36* 我一點也不擔心我的病						IP36.
IP37 事實上，得這個病讓我十分煩惱焦慮						IP37.
IP38 其實我心裡十分害怕我得的這個病						IP38.

您患病的原因

人們對為什麼生病有不同的看法，我們想知道您的看法如何。請注意，以下問題並沒有一定的答案，因此，不論医生、或是您的家人怎麼說，我們想知道的，只是您自己的看法。以下問題請在與您想法最接近的答案空格內打**(√)**。

我認為讓我生病的原因是……..	完全不同意	不同意	沒意見	同意	非常同意	
C1 壓力或煩惱						IPC1.
C2 遺傳 (家族性)						IPC2.
C3 細菌或病毒引起						IPC3.
C4 食物或飲食習慣						IPC4.
C5 純粹個人運氣，可能是我倒楣						IPC5.
C6 過去不良的醫療結果						IPC6.
C7 環境汙染						IPC7.
C8 由於我自己的行為所導致						IPC8.
C9 我的心態問題，例如，我對人生想法太悲觀						IPC9.
C10 家庭問題、或過度煩惱所致						IPC10.

我認為讓我生病的原因是……..	完全不同意	不同意	沒意見	同意	非常同意	
C11 工作過勞						IPC11.
C12 由於我情緒不好，比如說我常感覺沮喪、寂寞、焦慮、或空虛						IPC12.
C13 自然的老化過程						IPC13.
C14 飲酒						IPC14.
C15 抽煙						IPC15.
C16 意外或受傷						IPC16.
C17 因為我個人的性格所導致						IPC17.
C18 因為我的免疫力不如從前						IPC18.

最後，在以下空格中，請依次填 入**三個您認為最可能導致您生病的因**。您可以自上頁所列因素中選擇，或是填入其他您認為最可能的因素。我認為最有可能使我患病的原因是:

第一 _____

第二 _____

第三 _____

Appendix 9 The Illness Perception Questionnaire (IPQ-R)

(Moss-Morris et al., 2002)

Name…… Date……

YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your
illness. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness. I have experienced this symptom *since my illness*

This symptom is *related to my illness*

Pain	Yes No	_____	Yes No
Sore Throat	Yes No	_____	Yes No
Nausea	Yes No	_____	Yes No
Breathlessness	Yes No	_____	Yes No
Weight Loss	Yes No	_____	Yes No
Fatigue	Yes No	_____	Yes No
Stiff Joints	Yes No	_____	Yes No
Sore Eyes	Yes No	_____	Yes No
Wheeziness	Yes No	_____	Yes No
Headaches	Yes No	_____	Yes No
Upset Stomach	Yes No	_____	Yes No
Sleep Difficulties	Yes No	_____	Yes No
Dizziness	Yes No	_____	Yes No
Loss of Strength	Yes No	_____	Yes No

We are interested in your own personal views of how you now see your current illness. Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

VIEWS ABOUT YOUR ILLNESS STRONGLY DISAGREE DISAGREE NEITHER AGREE NOR DISAGREE AGREE STRONGLY AGREE

IP1 My illness will last a short time
IP2 My illness is likely to be permanent rather than temporary
IP3 My illness will last for a long time
IP4 This illness will pass quickly
IP5 I expect to have this illness for the rest of my life
IP6 My illness is a serious condition

VIEWS ABOUT YOUR ILLNESS STRONGLY DISAGREE DISAGREE NEITHER AGREE NOR DISAGREE AGREE STRONGLY AGREE

IP7 My illness has major consequences on my life
IP8 My illness does not have much effect on my life
IP9 My illness strongly affects the way others see me
IP10 My illness has serious financial consequences
IP11 My illness causes difficulties for those who are close to me
IP12 There is a lot which I can do to control my symptoms
IP13 What I do can determine whether my illness gets better or worse
IP14 The course of my illness depends on me
IP15 Nothing I do will affect my illness
IP16 I have the power to influence my illness

IP17 My actions will have no affect on the outcome of my illness
IP18 My illness will improve in time
IP19 There is very little that can be done to improve my illness
IP20 My treatment will be effective in curing my illness
IP21 The negative effects of my illness can be prevented (avoided) by my treatment
IP22 My treatment can control my illness
IP23 There is nothing which can help my condition
IP24 The symptoms of my condition are puzzling tome
IP25 My illness is a mystery to me
IP26 I don't understand my illness
IP27 My illness doesn't make any sense to me
IP28 I have a clear picture or understanding of my condition
IP29 The symptoms of my illness change a great deal from day to day
IP30 My symptoms come and go in cycles
IP31 My illness is very unpredictable
IP32 I go through cycles in which my illness gets better and worse.
IP33 I get depressed when I think about my illness
IP34 When I think about my illness I get upset
IP35 My illness makes me feel angry
IP36 My illness does not worry me
IP37 Having this illness makes me feel anxious
IP38 My illness makes me feel afraid

CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the
factors that caused your illness rather than what others including doctors or family may have suggested to
you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that
they were causes for you by ticking the appropriate box.

POSSIBLE CAUSES STRONGLY DISAGREE DISAGREE NEITHER AGREE NOR DISAGREE AGREE STRONGLY AGREE

C1 Stress or worry
C2 Hereditary - it runs in my family
C3 A Germ or virus
C4 Diet or eating habits
C5 Chance or bad luck
C6 Poor medical care in my past
C7 Pollution in the environment
C8 My own behaviour
C9 My mental attitude e.g. thinking about life negatively
C10 Family problems or worries caused my illness
C11 Overwork
C12 My emotional state e.g. feeling down, lonely, anxious, empty
C13 Ageing
C14 Alcohol
C15 Smoking
C16 Accident or injury
C17 My personality
C18 Altered immunity

In the table below, please list in rank-order the three most important factors that you now believe caused

YOUR illness. You may use any of the items from the box above, or you may have additional ideas of your
own.
The most important causes for me:-
1. _____
2. _____
3. _____

Appendix 10 The COPD Self-efficacy scale (Wigal *et al.* 1991)

Read each numbered item below, amid determine how confident you are that you could manage breathing difficulty or avoid breathing difficulty in that situation.

Use the following scale as a basis for your answers:
(a) = Very confident
(b) = Pretty confident
(c) = Somewhat confident
(d) = Not very confident
(e) = Not at all confident

1 . When I become too tired.
2. When there is humidity in the air.
3. When I go into cold weather from a warm place.
4. When I experience emotional stress or become upset.
5. When I go up stairs too fast.
6. When I try to deny that I have respiratory difficulties.
7. When I am around cigarette smoke.
8. When I become angry.
9. When I exercise or physically exert myself.
10. When I feel distressed about my life.
11. When I feel sexually inadequate or impotent.
12. When I am frustrated.
13. When I lift heavy objects.
14. When I begin to feel that someone is out to get me.
15. When I yell or scream.
16. When I am lying in bed.
17. During very hot or very cold weather.
18. When I laugh a lot.
19. When I do not follow a proper diet.
20. When I feel helpless.
21 . When I drink alcoholic beverages.
22. When I get an infection (throat, sinus, colds, the flu, etc).
23. When I feel detached from everyone and everything.
24. When I experience anxiety.
25. When I am around pollution.
26. When I overeat.
27. When I feel down or depressed.
28. When I breathe improperly.
29. When I exercise in a room that is poorly ventilated.
30. When I am afraid.
31 . When I experience the loss of a valued object or a loved one.
32. When there are problems in the home.
33. When I feel incompetent.
34. When I hurry or rush around.

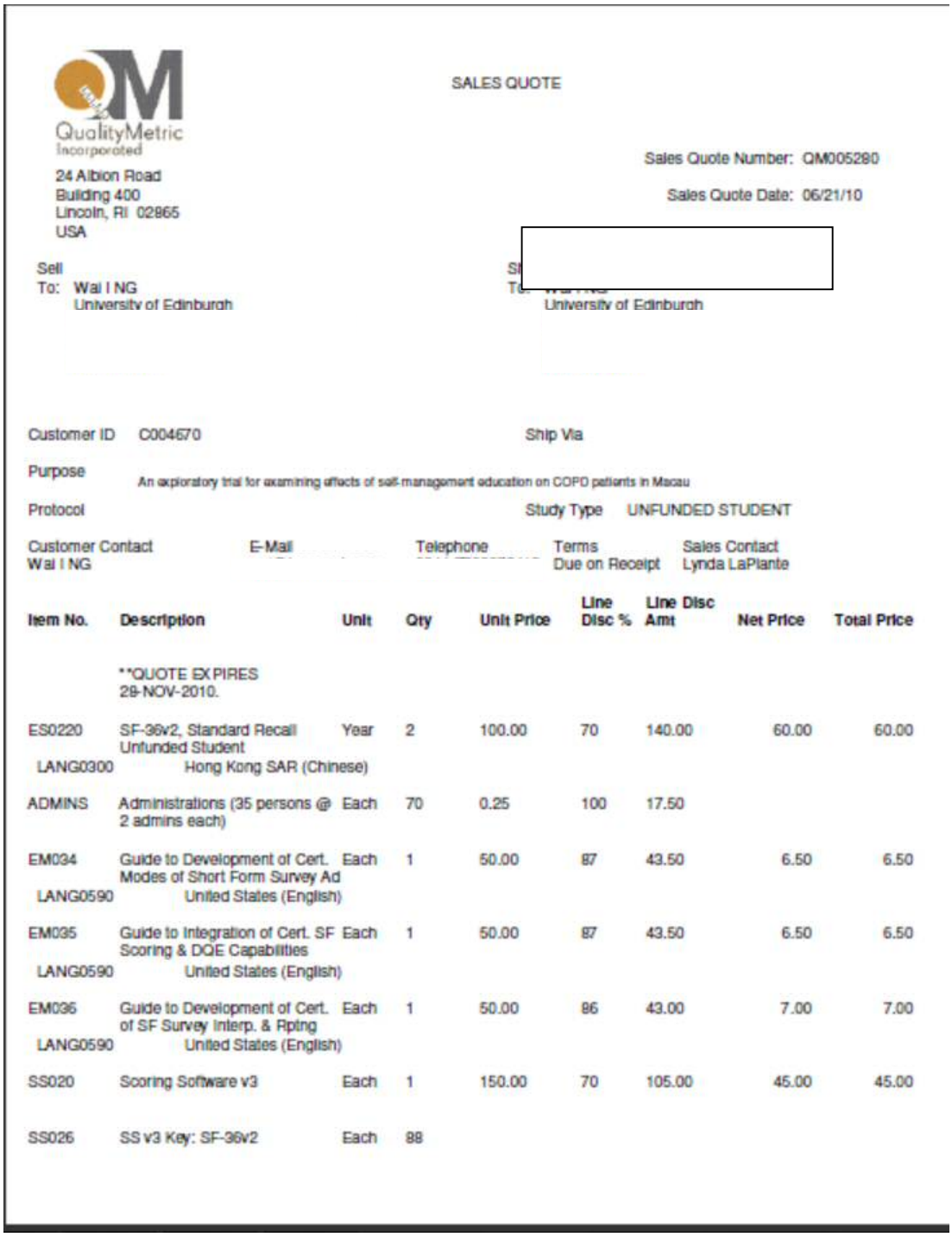
Appendix 11 Checklist for assessing inhalation technique

Metered-dose Inhaler technique Checklist

Participant No : Name of drug:

No.	Content of Procedures	Pre-assessment	Post-assessment	Follow-up assessment
1.	Tell the function of the drug			
2.	Check the expiry date of the inhaler			
3.	Shake the inhaler and open the lid			
4.	Slow breathing and make a slow and deep exhalation			
5.	Place the lips tightly around the mouthpiece of the inhaler			
6.	Breath in slowly and deeply at the time of pressing a dose of the inhaler			
7.	Hold the breath for 10 seconds or as long as possible			
8.	Breathe out			
9.*	If second dose is necessary, take a rest for 30 seconds before repeating step 4 to 8			
10.	Wrap the mouthpiece thoroughly with dry tissue			
11.	Cover the inhaler properly with the lid			
12.*	Always bring along the short-acting bronchodilator			
13.*	Rinse the mouth after inhaling			
Assessor's code: Total				

Appendix 12 Certificate for purchase for SF-36v2 Questionnaires



QualityMetric Incorporated
24 Albion Road
Building 400
Lincoln, RI 02865
USA

SALES QUOTE

Sales Quote Number: QM005280
Sales Quote Date: 06/21/10

Sell
To: Wai I NG
University of Edinburgh

University of Edinburgh

Customer ID C004670 Ship Via

Purpose An exploratory trial for examining effects of self-management education on COPD patients in Macau

Protocol Study Type UNFUNDED STUDENT

Customer Contact	E-Mail	Telephone	Terms	Sales Contact
Wai I NG			Due on Receipt	Lynda LaPlante

Item No.	Description	Unit	Qty	Unit Price	Line Disc %	Line Disc Amt	Net Price	Total Price
	**QUOTE EXPIRES 29-NOV-2010.							
ES0220	SF-36v2, Standard Recall Unfunded Student	Year	2	100.00	70	140.00	60.00	60.00
LANG0300	Hong Kong SAR (Chinese)							
ADMINS	Administrations (35 persons @ 2 admins each)	Each	70	0.25	100	17.50		
EM034	Guide to Development of Cert. Modes of Short Form Survey Ad	Each	1	50.00	87	43.50	6.50	6.50
LANG0590	United States (English)							
EM035	Guide to Integration of Cert. SF Scoring & DQE Capabilities	Each	1	50.00	87	43.50	6.50	6.50
LANG0590	United States (English)							
EM036	Guide to Development of Cert. of SF Survey Interp. & Rptng	Each	1	50.00	86	43.00	7.00	7.00
LANG0590	United States (English)							
SS020	Scoring Software v3	Each	1	150.00	70	105.00	45.00	45.00
SS026	SS v3 Key: SF-36v2	Each	88					

SALES QUOTE

24 Albion Road
Building 400
Lincoln, RI 02865
USA

Sales Quote Number: QM005280

Sales Quote Date: 06/21/10

Sell
To: Wai I NG
University of Edinburgh

Ship
To: Wai I NG
University of Edinburgh

Customer ID C004670

Ship Via

Purpose An exploratory trial for examining effects of self-management education on COPD patients in Macau

Protocol

Study Type UNFUNDED STUDENT

Customer Contact	E-Mail	Telephone	Terms	Sales Contact
Wai I NG			Due on Receipt	Lynda LaPlante

Item No.	Description	Unit	Qty	Unit Price	Line Disc %	Line Disc Amt	Net Price	Total Price
SS997	SS v3 Add-on: MSE							
SS999	SS v3 Add-on: RCI							

Amount Subject to Sales Tax	Amount Exempt from Sales Tax		
0.00	125.00	Subtotal:	125.00
		Tax:	0.00
		Total in USD:	125.00

Appendix 13 Topic guide for the focus group

Two main foci to be covered :

1) How do you find the self-management workshops?

Possible prompts:

- Are those content related to your daily management of your disease? And how?

- What content impressed you most?

- How do you find about the action plan? Difficult to carry out? Effectiveness?

- How do you find the delivery of the workshop? For example, time, venue, duration of the workshop.

2) What are your experiences of being self-managed with your disease?

Possible prompts:

- During exacerbations? Daily management? Before and after the programme

- How do you find the effectiveness of the management strategies you applied?

Overall Question

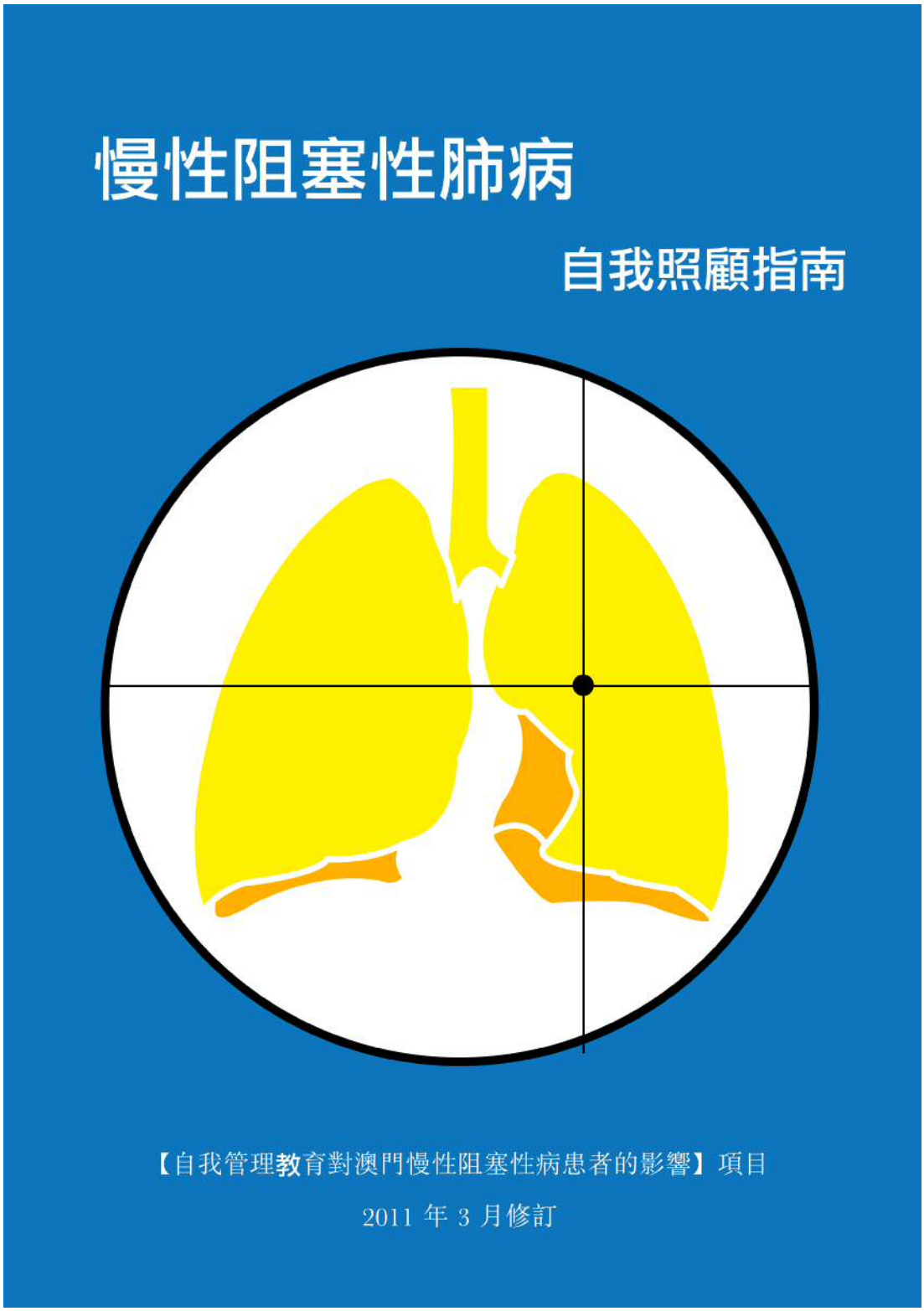
3) As a COPD patient, do you think conducting self-management education programme as such is necessary? If so, how should it be run?

Possible prompts:

- As a COPD patient, what do you most expect a nurse to do for you?

- Any further opinions and recommendations

Appendix 14 Patient Handbook



Appendix 15 Action Plan

GREEN Zone：Doing Well **Take these Long-Term Control Medicines Each Day**

- No cough, wheeze, chest tightness or shortness of breath during the day or night
- Can do usual activities

Medicine	How much to take	When to take it
_____	_____	_____
_____	_____	_____

Before exercise Take _____ □ 2 puff or □ 4 puff 5 to 60 minutes before exercise

YELLOW Zone: Getting Worse

- Cough, wheeze, chest tightness or shortness of breath, or
- Waking at night due to wheeze or
- Can do some, but not all Usual activities

First

_____□ 4 puff

**And keep taking your GREEN Zone medicine

If your symptoms persist after 1 hour of previous treatment

_____ □ 4 puff

** If your sputum appears yellowish or greenish, or increases in volume and thickness or you have fever, you may probably be infected

⇨ **Go to OUT-PATIENT**

RED Zone：Medical Alert

- Very short of breath, or
- Above management do not help
- Symptoms get worse in 24hrs

Go to the Hospital or Call for an ambulance NOW !!!!!!

Appendix 16 Transcript symbols

The interviews were transcribed with the application of Silverman's simplified transcription symbols (Silverman, 2011). The symbols could help to understand the dynamic of the interacted subjects during the interviewing process as well as to capture the contextual situation within the focus groups.

=	Equal signs, one at the end of a line and one at the beginning, indicate no gap between the two lines.
[ ]	Left brackets indicate the patient at which a current speaker's talk is overlapped by another's talk.
(.3)	Numbers in parentheses indicate elapsed time in silence in tenths of a second.
( )	Empty parentheses indicate inability to hear what was said.
(word)	Parenthesised words are possible hearings.
((word))	Double parenthese contain author's description rather than transcriptions.
WORD	Capitals indicate especially loud sounds relative to the surrounding talk.
<u>Word</u>	Underscoring indicates some form of stress, via pitch and / or amplitude.

On top of the above, I added two more symbols:

(*word*)	Italicized words in parentheses indicate facial, gestural or emotional expressions
…word	Three dots at the beginning of one's talk indicate continuing of his talk after interruption.

Appendix 17 Focus Group One Transcript (Sample)

Participants :

Code	Name	Age / Sex	COPD Staging	Education Level	Satisfaction (Total 65)
E008	Nick	61 / M	IV	Secondary	48
E010	Amy	57 / F	II	Primary	52
E014	Wilson	73/ M	II	Primary	60
E019	Ivan	73 / M	III	Primary	60

SL (2 - 2.55) First, would like to ask how you guys feel about the COPD self management workshop that took before? Any feeling to the workshop? Can you share?

19 Like acquired knowledge, related to the condition of the disease=

SL =Acquired knowledge related to the condition of the disease, Um..for example?

19 It means recuperation..

SL Recuperation……it means.. err? Whats the meaning of recuperation?

19 Recuperation means……..means…err…means, means…to try...how to control breathing.

SL Ar…how to control breathing..um..

19 And those….those taught us the Tai Chi exercise…those I have forgotten already.

SL Arr…can remember the Tai Chi exercise, although the content is forgotten, but those movement right? So, recuperation, control breathing and the understanding to the disease=

19 =Mainly about the understanding of the disease progress.

SL Understanding of the disease progress means which content?

19 Means how to…to..to.. regulate the health of your own self.

SL Recuperation in a self-based, mainly focus on recuperation. Um, good good good…or any other follow-up?.. any other..any other patients?

10 should do the similar things.

SL How to do it? How will you do it?

10 Like be cautious of your own self, as I did.

SL Be cautious of your own self..um….

10 Or most importantly to keep warm, don't catch a cold or the flu, something like that.

SL To carefully protect your own self, don't catch a cold or the flu.

10 Um..um..when I caught a cold or a flu, I would become…become…start becoming anxious and short of breath, that's how I work. It means, everyone's method is different.

SL Um..so, everyone has differernt needs, is that what you mean…?

10 Um Um

SL So, be carefully recuperating yourself, and that will stop worsening the symptoms.

10 Um um..

SL Um..then if there are still any content that you think you have learnt from the worksop?

10 Those things I have learnt..may be something I have forgotten from the workshop…and stopped doing those….something like working on deep breathing, that's something I keep doing…

SL Ooo, you have done deep breathing, alright, alright, anything apart from deep breathing? [19 Deep breathing is good..it's good..can help enlarging the lung volume..its real] Right right..deep breathing is helping. [10 Went and visited Doctor, Dr. Yeung kept saying: "remember".. "remember" .. always reminded me for keep working on it!] I see, I see…Dr. Yeung also reminded you to work on it..UmUm…good, what about you Old Wong?

14 O about myself, ..for me..like sometimes I might get tired during my work, then I would take a break and worked on deep breathing again…Ar…things like walking on stairs, doing housework at home, I also follow her instruction then really became easier, but working through morning exercises, then..sometimes could learn what she taught us to do, sometimes would work on those breathing exercise myself, work on those little gestures…then…ha..then…it means the physical condition became progressively progressively better..ha=

SL =O..you have tried the controlled breathing?

14 Yes…like work on those little gestures..=

SL = Learnt incompletely…but the general situation is known=

14 =Yes…yes… worked on something like these…now at work didn't feel it..not so suffering…even long-distance walk is ok now, at the beginning in the past was not ok=

SL =At the beginning was suffering=

14 =At the beginning if walk for too long is not possible, now during the walk…in the past when I went to Gongbei Port, I would need 5 to 6 breaks for arriving the port…now is a bit better, its ok to walk for long..walk…means now I can continuously for around an hour=

SL =You think it is related to the exercises and deep-breathing that's you have done?=

14 =Yes Yes…related…or take good care of own self during bad weather, something like health care by own self.

SL Some precaution..er..some method for self-health-care during worsening of the disease…..orr, it's quite good, learnt quite a lot.

14 Yes, really could learn a lot, it's all because of Nurse MN..haha.

SL Um…that's great that's great! Then what about Nick?

8 We know what is COPD through the workshop, in the past it's not clear what kind of disease we are suffering from.

SL O…really?

8 In the past what I know is coughing, lots of mucous..something like in thebody is in the situation of heatiness, then now after attending the workshop know this is COPD..ha…So, in terms of learning, we have Nurse MN for explaining the disease to us patiently, in addition to the therapy from the doctors..although my disease is comparatively severe, because I have this disease for 20 years already, when I counted, it does have 20 year, but I have not been aware in the past, and think that keep taking fresh air and traditional Chinese Medicine sometimes would fix the problem. Then eventually became serious…I was working and comparably busy that time, went usually for injection, injection is for emergency case, means an one-off medication, intravenous injection, then became receiving the intravenous injection every 2 days, worsening the situation…made me can't work anymore and I am

suffering from it, I had a job before.

SL Then what about now? [8 now…]How do you feel after joining the workshop [8 after the workshop I learnt a lot, meanwhile my situation became more serious, then after joining the workshop…it reminded us the things that should take precaution, mostly importantly is not to caught a flu.]

SL I see, most importantly not to catch a flu=

8 =Ar..most importantly not to caught a flu, because once the trachea was irritated.. .I am weak and there is nothing I can do….once caught a cold, I couldn't stand for that…ar, once couldn't stand for that, then have to go for injection, then then then everything, then hospitalized. Last year, I was hospitalized for 3 times.

SL O..so you learnt more about the disease through the workshop, like what is COPD and how to take care of yourself..I mean, self protection, and try not to worsen the situation=

8 =Um..Um, yes, yes….in this case, yes…

SL What else have you learnt?

8 What I have learnt is how to take care of myself with COPD, when my situation became serious, the most serious was I couldn't get out of bed, couldn't go shitting, couldn't eat, walking is no way. I've tried using wheelchair to go to the Port with the help of my wife. Ha, the above was my condition last year. But now, different aspects, for example, medical support…..as I am now following up at the government hospital, as well as hospital in Zhuhai. I have also been to Lee Ka Shing Hospital in ZanTao, my home town, and was hospitalized there. Then I consulted the experts, but I'm told that my disease is already in a comparatively severe stage.

SL I means you know that your situation became more serious=

8 =Tried lung function assessment, reported that I am with severe pulmonary emphysema, the respiratory system is at level 2, level 2 in lung failure ((Type II respiratory failure)), also( ) it is difficult for curing this disease; now I am using antihypertensive drug, it is usually doing fine, but if I was having a flu, my blood pressure and heart rate would increase=

SL (3.1 – 11:38) =So you learnt from the workshop that you have to be aware of controlling the situation of your flu..[8 Um, um, um] O, right..ar…you have tired the workshop last year, ar, what do you think about the time arrangement of the workshop?=

8 =Its quite good! Because, after the learning…you...you.. I mean work on nothing

now, I can't work on anything anyway..ar..so now..usually in the morning…I…I go for a walk in the park cause I am living in the area of NAPE.

SL Then how do you feel about the workshop? Maybe Ivan, what do you think about the time arrangement of the workshop? Maybe divded into 2 parts? Since some learners can acquire the skills in 2 parts. But some of learners may need 3 parts for the learning, is dividing the workshop into parts helpful for you to pick up the management skills for self-caring? Is it too frequent? Or is it not enough?

8 Its quite good, through the learning, I know what is going on, on top of that, there are guidance provided by expertise like Nurse MN, then I know what is going on..I..I…understand the illness condition is like this, what I should do. Ar, now is using pharmaceutical therapy, now Iam..I have bought a machine…those machine for delivering oxygen, I means it is always needed, I was told by the doctor to keep under oxygen therapy all the time or at least 15 hours. But I was not able to sit there for such a long time, so I just used the oxygen when I felt difficulty in breathing, I didn't use it when I didn't feel short of breath. However, I have no choice now, I have to use oxygen even when I am sleeping.

SL Um, what about Wilson, what do you think about the learning time for the workshop? How many lessons have you taken?

14 I…I've forgotten how many[8 Many lessons…I remember almost 4, to5] lesson I've taken.

SL I see, taken as many as 4 to5 lessons. What about Amy?

10 The timing.....

SL Ivan, how many lessons have you taken?

19 Seems like 3 lessons.

SL I see, 3 lessons..do you think if 3 lessons are enough?Is it too frequent or not enough?

19 O, its enough.

SL its enough..!? It's enough..!? what about 2 lessons? Anyone has taken 2 lessons?

10 I have 2 lessons.

SL You have 2 lessons, were 2 lessons enough?

10 My problem is the time, so I could only attend 2 lessons

SL I see, I see…then what do you think about the 2-lessons or the 3-lessons arrangement? I mean about the workshop?

8 In general, it is fine. It is indeed a matter of taking care of your own disease.....it is mainly teaching us people acknowledge the characteristics of the disease, and what do we have to pay attention, the most important thing is on us, that is all.

SL (3.2 – 14:10) So you think both 2 or3 lessons should be enough, then what about the venue? Is it convenience to you with holding the workshop in the section of outpatients of KWH? Is the venue comfortably arranged? Ar..or any other opinion?

.

14 I think the previous venue [19 No problem] is easier to be found [8 If you got the chance of ( )] and more spacious, that's my opinion.

SL I see..Isee…think that the First Out-patient department is easier to be found, but the present venue is more spacious?

14 No..

SL I see, that place, where the previous..er..seminar was held?

14 Yes, where the seminar hold….haha…haha

SL I see…good good…what about Amy?

OB She was specially arranged, she was at the outpatients, taken the workshop in a clinic.

SL I see…it means she took the workshop separately. So, in general the venue is fine, right, right!? It's ok…haha!

19 it's ok.

SL (2.1 – 15:45) Alright…so, you guys have just shared quite a lot of content that taught by Nurse MN, they are more or less emphasized on deep breathing, some of them about exercises, some of them about self-recuperation and knowledge of the disease, right? If there are any parts in the workshop which are most impressive to you?

10 You mean which parts?

SL The content of the lesson, since there are so many…

10 I see, the teaching content….since we don't know nothing in the beginning, then of course, we will have more understanding about the disease only after being taught, something like that.

SL In which way you mean?

10 Its like in the beginning don't know anything about that disease, ha..like this..

SL I see….understanding of the disease…

10 Ar, don't know it is like this not until it became like this, so got to start protecting myself now.

SL Um..um..then, it means the understanding of disease impress you most. Well, maybe Old Wong, which part of the course is most impressive to you, amongst the teaching content.

14 It means…taught me those, I am impressed by the breathing [8 Breathing… really…]

SL Um..breathing, about how to breath?

14 It is (*participant demonstrats*) the breathing that involves breathing in and breathing out. Arh..then to the lung it is….[19 It means good to the lung function] more comfortable [19 For lung inflation] For those moments I was able to learn, I followed the instruction, for those I couldn't remember, I did it in free style with my own movements.

SL In what way do you mean?

14 Hahaha…it means those…movements that freely done by myself.

SL Which particular style do you mean? Cause Nurse MN has taught you guys several movements…

14 Ha, I've forgotten most of those movements…hahaha (*everyone laughs*).

SL Mostly forgotten..haha!

19 Not good at memory…hahaha..

SL Because apart from those health exercise, breathing exercise, there are some others about energy saving, those movement that help saving energy=

8 =Yes, those technique, breathing technique, energy saving technique

SL Those techniques, yes, those techniques, which particular you could remember?

14 Haha…some of them can be remembered, but not much memory about them now, mostly do it myself in free-style….

(*Every one laughed*)

8 Free-style

14 Move freely

SL Arh..but you think it is still useful?=

14 =Useful! When you worked on whatever movements..[19 Its useful!...Those techniques, it means understand more about the disease] If they… are teaching sincerely, of course you would be taught something beneficial and useful, it is definitely great if you can do it yourself, but there so many to remember, how to remember.. hahaha

SL I see..then, then, it means it's a bit pity that something learnt from the workshop has forgotten, right?

14 That's right.

SL O right, what about Ivan? Which part of the content impressed you most? Amongst all those content that taught in the workshop?

19 I am most impressed by breathing in and breathing out, it's good for lung function.

SL I see, breathing, those involve breathing out, that's true, it's good to the lung…O…what made you having such a feeling?

19 It means the feeling of..you are long-term, it's better now for lung inflation when taking deep breathing; In the past when I was smoking, my lung could not be expanded even I took a deep breath, now is really better, my chest expanded when I was deep breathing, I could feel it.

SL I see, you could feel it yourself, that lung inflation was really taking place, after controlled breathing, it is helpful to your lung function, you felt it, it's really good that you have the feeling as such=

19 =Nonetheless, it's yourself who don't smoke, its real…

SL Haha..

19 Haha..

SL It's not bad, this workshop taught you how to taking care of yourself in daily habit, right?

19 That's right.

SL Not bad, not bad. Then…Nick? What impressed you most?

8 It's…it's still those breathing technique, and also those breathing at night, the night exercises, need to do it before sleep, they are those involving breath out and breath in, I do it every night and do it before sleep. But my, my…lung function is really worse, I am already in…the doctor said in level 2 of failure in breathing function, I tried to understand, to see if the situation could be improved by surgery, but the advice is better not to do so, you can tried, not impossible, and said would be troublesome, and got to be assessed in advance, this operation can be done in Xiamen and Hong Kong, I have enquired, but still better not to do so..

SL So you think after the deep breathing before sleep is helpful to this..

8 Yes….sometimes about how to cough up sputum..

SL Ar, expectorate, how to cough sputum up? Can you guys share a bit? How come this part is impressive as well…ha!?

8 Its always difficult for us to cough the sputum up, not enough strength to do so, if tried several times will become short of breath, sometimes..sometimes I drank some water, sometimes sat down and patted my back, then have got use my strength, the workshop taught us how to save the energy, how to use the strength…and how to save the energy together with deep breath to force it out.

SL I see..mainly the coughing technique..right?

8 Yes..yes..

SL You've just mentioned energy saving, anything about energy saving technique impress you?

8 It does, it does, energy saving means in order to breath smoothly, you have to breath in and breath out, usually, when I inhaled oxygen, I would exhaled more oxygen out, but all this technique …have been taught when I was hospitalized in KWH

during 2005.

SL Then it means you keep using this method..I see, that's not bad..then..er..Right..let me make a brief conclusion first….just before everyone of you mentioned the key points from your learning , for example, breathing, how to control the breath, a breath focusing on breathing out, right? A breath that breathing out deeply, right? [8 Yes] Another thing is exercises, you guys have mentioned…you know the breathing exercise, it means you guy worked on those movements for breathing as well, right? And that its impressive, right? Also, something about precaution of preventing worsening the condition of the disease. How to protect yourself from being attacked by the flu easily, right? Then…er..er..there is something like, as you guys just mentioned, the energy saving methods and techniques.. er.. er…or something about the skills of coughing and expectoration ..er..er..actually in the workshop there are contents other then these, such as something about the skills for using inhalation drugs, do you remember anything about that?

8 (.2) I have to do the inhalation all the time…..now the doctor teaches us this knowledge, as well as the workshop here, have to teach according to the instruction, otherwise you practice incorrectly.

SL You have followed the instruction for drug inhalation…Ha, is everyone here also…right Wilson have not used this drug inhalation, Amy, you used it, have you followed the instruction?

10 Yes, I take it in the morning and in the night.

SL In the morning and the night…umum, what about the technique of inhalation? For example, have you followed the instruction of how to breath in and breath out during inhalation?

10 Before inhalation got to breath out, then breath out slowly after inhalation.

SL Umum….

10 Most importantly is mouth rinsing after inhalation.

SL Mouth rinsing after inhalation, that's correct that's correct…you still remembered, still remembered.

10 Um.

Then…Ivan? Can you remember?

19 Remember! (*coughed…*) Breath in from the nose and breath out through the mouth.

SL Umumum…still remember. Nick, you have done this too.

8 I remember…I need to take it every day. The one called Seretide has to be inhaled every morning after waking up and every night before going to bed, so two times in total. Then, for the one which normally is taken at 3pm in the afternoon, we called it ShuLok Wa in the mainland and it is called Spiriva here, it is round in shape and is covered by pushing the lid, I'm also using it now, thus I'm using these two medication at the moment.

SL Great, then if there is any, any short-of-breath management, would you guys also remember? Short-of-breath management means do you know what to do when encountering difficulty in breathing.

10 (.2) Nurse taught me to use that pipe ((metered-dose inhaler, MDI)).

SL You even have the pipe ((MDI))?

10 I have, for the precaution of short of breath.

SL Good, good good. This one is also related to short-of-breath management, any other things you have learnt concerning the short of breath situation?

8 (*Short-acting agonist*) O this one, this one…[10 I seldom use this one, seldomly us, use it only for a precaution purpose, do this in the morning] In the past, I used it only in emergency situation, but now I keep it with me wherever I go sometimes, use it when having difficulty in breathing. I used once just before I came here, before I used even for 4 times per day.

SL Umum…Ivan? Ivan can you remember anything about the short-of-breath management?

19 Short-of-breath management? Means the time of the walking motion?

SL It means, what would you do when you encounter difficulty in breathing during any of your activities?

10 Then I myself…if this situation happened when I am walking up stairs, I will stop walking, take a little break, wait till the situation is relieved and become…not…not so serious…then I start climbing up the stairs again.

SL Um, I see I see. It means stop and take a rest=

10 =If keep walking steadily on blading surface. Distance is not a problem. So, it happen usually when I was climbing up stairs, it was like after climbing up for around

3 steps, I encountered a little bit of difficulty in breathing, mainly because of myself…I felt I have to stop, then I stop.

SL Umum, I see I see, then Old Wong? Anything else about short-of-breath management?

14 Well, no big problem so far, I keep climbing up stairs every day.

SL So this short of breath situation is not frequently happened, right? Good good good. Then what about dietary, you guys have not mentioned dietary much, do you still remember this content that taught in the workshop?=

8 =Yes yes yes…got to take some non-greasy food, like those prepared from steaming or stewing..also with some vegetables, it means, don't take too much food with high CO_2 content, something like this.

SL Ar…you can well remember the CO_2 concept, quite good. Then what kind of food contains more CO_2, should be avoided? And which type better take more? Do you guys...remember?

8 Rice is one of those, rice contains lots of CO_2, those related to starch.

SL Starch, rice…yes yes…good good good, anything else?

8 Those vegetables and fruits are better.

SL Take more vegetables, fruits, not so greasy; anything else?

14 Um…not much, avoiding something like those with high cholesterol content. Only take a tiny amount and not so frequently…don't take it too often…ha…usually we take vegetables and fishes and not that much for those with high cholesterol. We also take less meat, maybe sometimes will have some, should not totally stop eating meat, and got have some from time to time…..hahaha!

SL Ha..then Amy, anything else?

10 I am the same, more or less like that.

SL How similar?

10 Means less meat but more fishes.

SL Umumum….Ivan?

19 (.2) The same…having more like vegetables and fruits.

SL More vegetables and fruits, quite good, you guys actually have learnt something, right?!

8 I've quitted alcohol and smoking, just sometimes having a bit of tea, nothing more, not much digestion now.

SL (2.2 – 29:40) That's good, that's good..ok, another question..which part of the course is the most important in your daily life? It means, most helpful and and related?...So, you guys have just revised the different contents and parts that you learnt from the workshop, right!? Then which part of those knowledge is the most..related to your daily life?

(.5)

SL Maybe different person will have different answer, no need to be the same, it means, which parts that you learnt from the workshop most related to your own daily life? Which one?

(.6)

14 Those involving learning..?

SL Yes..there are so many things that you've learnt.

10 Most important is those about short of breath.

SL Most important is stop the condition of short of breath..I see..how to stop it?

10 For me, when I was working…I found it difficult to breath when I became nervous..[8 yes] So weird. Once relaxed, I became totally fine and seems like nothing happened, also when walking up a slope, I'll have become short of breath again if I walked for too long, then I have to walked slower, dare not to increase the speed.

SL Then do you think it is a kind of skills for saving your energy?

10 This seems not related to energy saving or not, sometimes the most important factor is yourself, just like what I just said, when you found it difficult to breath in a fast walk, then you have to stop, put it this way…stopped for awhile, then walked again slowly, its quite good, nothing serious happened afterward; sometimes when hurrying for doing something or going somewhere and became nervous ( ), then short of breath again, so shitty! It's totally fine when I was slow down and relax, would not have problem in breathing all day long.

SL Then it means you have learnt the skills to stop yourself of having short of breath, it is always the most impressive if what you've learnt can be applied to the daily life..its good, this example is special, very special…helpful!

10 Yes, its right, a bit special.

SL If there is anything else in what you have learnt is related to your daily life? Which parts?

8 The most important to me is don't get nervous…yes…like keeping a relaxed mind, and work slowly, then everything will be fine. If I have an appointment with the others…I'm not like this before, now when I have an appointment with the others, I will become…..nervous, when I become nervous...when you...I used to have this characteristic of getting nervous easily, when I am nervous, I will walk faster, sometimes will not think of slowing down, want to walk faster and faster, eventually..eventually eventuallly eventually..[10 short of breath] short of breath.

(*All nod their heads*)

SL Ooo…you guys have the similar feeling [8 that's serious] [19 I am not scared of walking on blading surface, but once on the stairs, I am scared.]

SL I see=

8 =I can't walk on stairs, it happened years ago, fortunately there are lift at mine, If I have to walk through stairs for doing something, I would just give up.

SL But still you learnt from the workshop that to slow down, and stop making yourself easily become short of breath=

19 =Yes, got to be slow in making a movement.

SL Slower in making a movement, now you can applied what you've learnt from the workshop into daily life [8 This is the most important point, can't hurry, once hurry, everything is gone] Is it correct, Wilson?

14 I am already old, then of course everything is slowed down…haha..haha..**JUST TAKE IT EASY=**.

SL =I see I see…that's good, that's good. Apart from slowing down during walking that stop the condition of short of breath, anything else from the workshop could be applied to daily life?=

10 =Maybe I am sensitive to something…when I smelled something strange, those symptoms like coughing would be triggered..then I would get sick. I am very sensitive,

once I smell something, my situation will get worse.

SL It means sensitivity…to sense any changes to your body and what triggers short of breath?=

10 =Its fast, once I smelled something, I will get worse immediately, anyway, if I smelled something wrong, I will , anyway its very fast, it's not ok like this.

SL Umum..then will you consider this is a kind of surveillance of symptoms...your sensitivity is higher?

10 (.2) Yes, not so fast in the past, since...now went I smelled it, when smelled it I started feeling sick..it is like this.

SL Yes…actually you have learnt from the workshop that you should play attention to this issue,to avoid, to take precaution.

10 Yes

SL (2.3 – 34:15) I see I see..its good. If that's all for this issue, I would like to ask, there is an item called the Action Plan in the content of the workshop, it means if the symptoms can't be relieved during exacerbation, you guys were taught to use the anti-wheeze drug, for 4 dosages, then take an 1-hour self-observation before the use of a further 4 dosages, still remember?=

8, 10 =Yes..Yes..it was mentioned.

SL It was mentioned…what about the 2 gentlemen here? Wilson? Ivan?

14 I have not tried that, so can't remember..haha.

19 I have tried.

SL Anything remember about the content?

19 Yes.

SL Can remember…have not tried. Ar, someone have tried, someone have not tried. Ok, then could each one of you share something about this topic. Ar, Nick, why you tried this method?

8 I frequently try this.

SL Frequently try…using particularly this one? 4 dosages, 1-hour self-observation, if not working, then 4 more dosages afterward!?

8 For me, I have tried this method in the past sometimes…I tried when I was wheezing, very efficient…Um…this is my experience when I initially used this, then before…,few years ago I used the 舒樂靈((ventolin))…err…used it during wheezing only…[SL you only use it during wheezing] Err…then in the class we were also taught to use it during short of breath…can use 4 dosages.

SL Have you tried?

8 Yes yes yes, I have, I didn't use if it is not serious sometimes, I am not using this that often now, I will not used those unless I'm required to use much force.

SL How do you feel about the effect?

8 It was better in the beginning, now seems like becoming becoming...becoming feel that now, seems like, maybe my condition became more serious, seems like not so useful, but it's still good to surpress the symptoms for a bit, sometimes it happened when I was walking on the road, I also stood for a while and stopped for a while, so, I seldom go to places which is far away now.

SL Umum, then do you think this method of using 4 dosages during wheezing, then 1-hour self-observation, then 4 more dosages afterward is helpful..er er..when responding to the exacerbation?

8 (.2) Still fine…after I sprayed for 2 times I sat still, lie down, sat still, once recovered, then..then..then..no need to use it again.

SL Any difficulties when doing this?

8 I take with me wherever I go.

SL You keep it with you all of the time.

8 I have I have I have…I keep it with me even when I was going out.

SL I see, then, what about Amy? Have you tired by following the instruction of this Action Plan..

10 I have not inhaled so many times [SL You have not inhaled so many times] I mean I am using it ((Seretide,舒悅泰)) in the morning and at night, so now for the one ((MDI)), I use one more time in the morning.

SL This Action Plan aimed at using the drugs during exacerbation only.

10 I take it as a precaution before exacerbation.

SL I see, precaution before exacerbation, followed the doctor's guidance, and you followed your habit with a designated time frame.

10 Well..it's mostly used just once, in the morning=

SL =Then, have you ever tried the 4 dosages method when you found difficult in breathing?

10 No.

SL I see...never tried, why? Ar, what's the problem in doing this?

10 No..not because of having problem, it's just I felt that there was no exacerbation.

SL O, during exacerbation! I mean the reason of not trying this method during exacerbation, what is it...?

10 Anyway, I didn't find difficulty in breathing when I was walking, something like this; If I became a bit nervous, it exacerbated for a bit, once I sat down, it stopped, then the problem is gone, it is like this..

SL I see, the symptoms relieved by taking a break…I see I see…so you [10 Um, anyway the most important point is, don't get myself nervous, personally I'm solving the problem in this way.] So you have never followed the drugs-controlling method?

10 Um..um…I have not tried so many dosage, so I used one more in the morning.

SL Um, got it, got it. What about Ivan? Have you tried this…

19 I..I seldomly wheezed, I'm like..like going up slopes..like going up stairs. Once wheezed, I stopped for a while then the symptoms were gone, no problem=

8 =Not that serious=

SL =Ar…just like Amy, stopped when wheezed…

19 I have not tried inhaling those gases, but those with the shape as an UFO, I approximately take once every 2 days.

SL I see, once every 2 days [10 You take once every 2 days, for me it is twice per day] Um, um, um.

8 (.3) The instruction is twice per day=

19 =I really seldomly wheezed, only a little bit when I was going up stairs fast, not that serious.

10 (*low voice*) It varies between people.

SL (2.4 – 39:27) Um, got it, both of you could relieve the symptoms by asking a break, so have never followed the guidelines of the Action Plan. Um, understand. Then maybe we can talk about some of the teaching methods in the workshop. Er…Do you guys still remember how Nurse MN taught you guys the various skills? Still remember? How Nurse MN taught you guys, what kind of methods?

8 Like taught…like the drug using skills?

SL Anything, teaching you how to use the drug is one of them.

8 There are some, like those concerning the dosage for using the drugs, how to use them, and got to clean up after medication, all these..all these..all these were taught.

SL O, how did Nurse MN tell you all these?

8 By using the samples, there are so many samples by that time..

SL Ar, samples, she did it by showing you the samples=

8 =Showed the samples, gave them to us…demonstrate to us…then we followed what she did. People like myself, never followed the instructions. In the past decade, I used the same drugs, the UFO ((Seretide)) one I've been using for 10 years=

SL =Ar…I found that there are so many things on your desk…haha..What are they? The book in blue, what's that?

8 This one ? [SL Is it given by Nurse MN?] Well,in the past, I have to fill it in.

SL I see..I see, you do fill in this, You have done the record [8 Yes, yes, yes, here..] Then it was the leaflet that given to you by Nurse MN, right?

8 Here(*open the leaflet*) taught us how to fill it in.

SL I see, you have done the homework, right, right!

8 Cause I'm comparatively serious, so I know more about those things.

Sl Um, I see I see. Ar, so you remember Nurse MN has showed you some samples, right?

8 Yes, yes.

SL Then has told you, demonstrated to you, right?

8 Um.

SL Then have you practice together with Nurse MN in the workshop?=

8 =Taught us to do the exercises.

SL Taught you guys exercises…alright… Showed you guys and then you guys repeat..?=

8 =Yes yes yes…there was a TV showing all those.

SL There was a TV, showing you guys the video.

8 Yes yes yes…there is also an instruction sheet which I've forgotten to bring it, with quite a lot of styles, seems to be 8 of them [19 haha…]

SL Those with 8 styles, those breathing exercises…your information is quite complete. Right…so Nurse MN has used so many methods to teach you, could you learn anything, was it helpful to you?=

8 =Yes, a little bit [( ) a bit] It's not possible to be ((learn)) 100%.

10, 8 couldn't learn them all.

8 Well, sometimes I tried that energy saving skills, work on a little bit of those exercises, also tried the night exercises, although I cannot perform all steps, I still had exercise….I also play those ((gymnastic instruments in the park)), these are all I do, no others.

(*All giggle*)

SL Ivan, anything else?

19 Quite the same…haha! Can't remember those Tai Chi styles…really can't remember, not good at memorizing things…hahaha

10 Quite the same.

SL Hahaha…so its quite the same for everyone.

8 I am not a patient person, one day my wife did the Tai Chi, I just don't know how to do it [19 Those those those…5 style…hahaha]=

SL =Those 5 styles…haha…then there seems to be one follow-up telephone interview, called and updated your condition=

8 =Yes yes yes, Nurse MN is really good in this [10 she did, um um] Sometimes called and asked for my situation.

SL How do you feel?=

8 =It's quite good, very caring for us. We...patients don't really know those knowledge, it is due to my personality. Rare.....I rarely participate in complicated activities now. In the past, we work all the time in the Mainland since I had business there and I needed to travel a lot by that time, alternatively I cannot participate in any activities already.

SL Then what about Wilson? How do you feel about the follow-up telephone interview from Nurse MN [14 She she she] How was it?

14 She sometimes called me from time to time and updated my situation, we do appreciate her consideration to us.

SL Ar…is it helpful to your learning? I mean, would it strengthen or help remind you the knowledge that you have learnt? Any effects that help your learning?

14 Yes yes, there were of course some effects, I mean followed her instruction and worked on it…to help keep my body well…more scientific.

SL Ar…it means followed her instruction, what you mean is she could remind you? Right?

14 Yes yes..

SL It's not bad. What about Ivan? About this follow-up telephone interview…

19 Follow-up telephone interview is quite food.

SL also good..?

19 I mean she cares for us.

SL Then what about your learning, anything helpful to that?

19 Yes, it's helpful.

SL How did it help you? How did it help your learning?

19 It is..err…making the lung function better.

SL I see, I see, Isee…then…then…umum, then you guys respond to the workshop are quite..quite the same. Actually do you think the self-management workshop for COPD…er…should it be or put it this way…which organization to conduct or which location to held this kind of workshop, that you think would be helpful to you illness control?

8 It would be the best if the government could organize more of these functions, There are so many COPD patients nowadays..so many, when I was in the park I saw every of the elderly there were having this disease, some of them didn't know their trachea is not alright, the lung is not alright, that's the situation. In fact, nowadays there are so many diseases, as well as COPD are are are…are quite a lot…now I think…

SL I see..feel that it will be better if it can be arranged by the government.

8 Yes…more promotion from the government.

SL Increasing government's promotion.

8 In the past we smoke, nowadays people seldomly smoke already, but still there are people who smoke

SL I see…it means the government's promotion to the community should be done, then do you mean there is a need for the workshop or management classes that held by the hospital, health center or Health Bureau is needed?

8 Also needed..also needed [SL also needed] These are also good…if people are taught about precaution as such, number of patients will be reduced in the future. This is, this is a kind of environmental problem, related to pollution, some related to job duty, some related to smoking

SL Um, them apart from what Nick just said something about the community, or if there is anything else or will that be better if these functions is targeted to certain specific category of people? Or where to do it? How to do it? Targeted to which kind of people? Anything like this…we can talk about it, it means is this kind of workshop useful in Macau?

(.4)

SL We have just mentioned that the government can do something for it, to promote to the community more about…the associated knowledge

8 Yes…knowledge…especially those professional kind..those kinds..something, maybe those constantly ((staying in)) polluted ((environment))..those…those workers

SL Those high-risk people, is that what you mean?

8 Umumum, these things are good….reduced the number of patients, is good to the country, good to the patient himself/herself. Now, may I tell you that having this kind of diseases really is suffering, first, is the loss of income resources, you…you can't work when you are having this kind of disease, even if you want to go for work! You just can't make any money, even though there are chances for you to make a big fortune, there is nothing you can do it! Sometimes, when I am wheezing….I would wheeze when I squat down. My disease is so severe that I sometimes really cannot reach things put high up [19 Can't use any force] Can't use any force, I have never been able to carry anything. Sometimes when I went shopping in the supermarket, very close to my home, I got some tissue paper there, I got difficulty in breathing when carried those stuffs and force myself into the lift.

SL I see, I see, then about that…

8 Sometimes, it didn't work even I <u>forced myself</u> to do so!

SL Yes yes yes…then about the workshop, which location do you think this kind of workshops should be necessarily be held?=

8 =General it is available in hospitals…if the authority can promote a bit more will be perfect.

SL Health authority?=

8 =Yes, health authority, health centre, also the government should provide more resources to the organizations.

SL What kind of organization?

8 Like…to the society organization….ar..more..more promotion, more learning opportunities related to the disease as such.

SL I see…means the different organizations in the society, especially those medical organizations are needed.

8 These issues are related to the environment.

SL I see, I see. Ok, we have talked for quite a while already..means about the contents of the workshop. So now would like to know how you guys control the condition of your lung disease in daily life? Can you guys share a bit?

(.2)

SL Means how did you control the condition of your lung disease?

8 (.2) About self-control…nowadays, this is different for different families [19 It means…take a normal life, take good rests…do more exercises, this is my opinion]

SL Umumum…if there is anything else?=

8 =It is needed….because it is always better to manage this kind of things by yourself, during exacerbation, you really can't do much. Like generally at the beginning we didn't play much attention to it neither, I myself did mine, sometimes you are not ok. You will not be ok once this kind of disease became serious, you totally couldn't stand for that when you found difficulty in breathing, how can you ask go for work in this case, just can't work.

SL Um..anything else Wilson, how did you usually manage your lung disease.

14 I myself…in terms of dietary…I myself..ar..be more careful.

SL For example?

14 It means…means the others….those..have…means should reduce those harmful food in the diet, don't take it. Ar..in this way will be better to the body.

SL It means play attention to the dietary [8 In term of dietary, nutrition is also important] Um, nutrition is important…umum., what about Amy?=

10 =I am the same, dietary is important.

SL Anything else guys? Apart from dietary..and taking more rest?

8 Dietary…weather is cold, most important is to keep yourself warm when the weather is cold, don't caught a cold, it's not ok once caught a cold.

SL I see..this is important as well, the method of self protection.

8 Cause coughing…once you cough, you are infected, the solution to infection nowadays is taking antibiotics, in addition we are now at 'high risk' weather, will be very dangerous once got sick.

SL Got it, got it…well…then usually what are the most effective methods for you guys to control the lung disease in daily life? Actually, we can discuss separately, it means any differences regarding this issue before and after attending the workshop? [8 Yes, there is] It means, any differences in the skills for controlling the ill lung before and after attending the workshop?

19 There is. Like comparing…like after the workshop…know more about the condition that I didn't know before attending the workshop, once attended, then you know more.

SL Which condition?

19 It means something like….how to…to maintain the lung function, etc. those involve breathing out and breathing in.

SL I see..breathing out and breathing in…to the maintenance of lung function, then it means, there are differences before and after the workshop …I see, it's like this. Err…anything else…er…it means err…what about your feeling?

8 It means I understand what kind of disease we are having through the workshop, the main problems of it, so, we learnt all these through the workshop, although it is dreadful, still if you play enough attention to all these, the lifespan are still able to be extended, can be treated well in time..

SL Quite positive towards the concept of self-management of the disease, right? Good good.

8 Umum…if not that I didn't pay much attention to this disease before, and I also didn't know the severity of it.....I feel that .....The living standard of nowadays is much better, even people with this disease can be prolonged life. Otherwise, it really could not be treated in 20 years ago... we would have no way to be treated before [14 incurable /((untreatable))…haha]

SL Haha, what about Wilson? Any differences in your daily control of the lung disease before and after the workshop?

14 If you had not attended the workshop, you did not know ….how to control your body. For now, the workshop teaches you how and how…..Well, although you don't …don't get all, to some extent, you know what it is about. Well, you execute in accord to it, then you become better in health. [SL Um, understood] If you don't know, you are so ignorant that you don't know what to do and which is good. Since there is workshop, you can learn what is good and then follow it…..haha!

SL Got it…It means you know the skills through the workshop, maybe couldn't

learn them all, but learnt as much as possible, right?

14 Exactly..

SL I see, that's good that's good…means it's helpful. What about Amy??=

10 =I am the same. Having no knowledge before the workshop, went to the emergency when it happened, got to went to the emergency immediately when it happened.

SL Went to the emergency immediately when it happened. What about now?

10 I don't scare now…he..

SL Don't scare now means..?

10 Cause no need to go frequently to the emergency now, it the past, it's almost like around a week, really=

SL =What are the reasons?

10 It means maybe I am now taking medicine, and doing those breathing exercises, those, I changed a bit of others. It's not easy to get cough or short of breath once changed..

SL Reducing the exacerbation rate, Ar..its nice. It means the number of times for going to the emergency is also reduced.. I see, very good. So, the methods that you guys just mentioned are all helpful to you, right? You guys pointed out that these methods are positive to lung function, to deep breathing and to the disease, right? Also the frequency of going to the emergency were reduced because you guys followed the instruction that guiding your dietary habit and self-management skills [10 Yes] right? Then it's very good, they are all helpful, right!? Er..er..again talk about exacerbation..er…er… are there any differences in managing the situation before and after the workshop? I mean, towards exacerbation, short of breath, cough, any differences in managing these situations before and after the workshop?

8 (.3) Yes, yes…

SL How?

8 It's like, now I understand what to do during exacerbation, or know which drugs to use I was having difficulty in breathing, sit down and take a break, anyway wait till the situation became stable, no need to take the ambulance immediately, no such a situation.

SL Umum..I see, it means similar to the situation as Amy=

8 =Cause I will sweat once nervous, I am strange in this, once sweated will want to go piss, I 've got this situation quite often. I'm very serious now, so can't…can't get nervous, nowadays my…so nowadays my wife are working no more and takes care of me

SL I see, it is like this. Ar, Ivan? Do you have any……any idea to share with us? Any differences between the way that you manage during exacerbation before and after the workshop?

19 (.4) For me……..exacerbation doesn't happen that often..not too frequent, rare. Never happen really.

SL Ar…it is like this. So just like what you've just said, the symptoms can be relieved by taking a rest. [19 That's it] I see, so the differences is not so obvious. I see, got it, what about Wilson?

14 Me…before the workshop, I didn't know how to relieve the symptoms by myself when I was suffering from walking.

SL O, didn't know how to relieve=

14 =Right, now with the skills that taught by Nurse MN…it is like, if suffering from walking…ar…control the breathing [8 (*Murmur*) The breathing skills] take a rest, then physically comparatively better, then not..not…not so, you know.

SL So, you have learnt some breathing and resting skills =

14 =Hehe…yes…if there is no one to teach you, you will not know how to relieve the symptoms, after the workshop then you know how to relieve, like controlling the breath, and taking a rest, then it becomes fine afterward

SL Um….ok, a brief conclusion, so, every one of you learnt from the workshop the skills for managing the short of breath situation, relieving the situation and even reduced the frequency for going into the emergency, right? It's quite good. Then, would like to have the last opinion from you guys, as a COPD patient, what kind of nursing service do you think would be helpful to you? Nursing service means, means what can we, the nurse, do to provide more help to you? Let's talk about it one by one

(.8)

SL Or some suggestions will also be ok! Give us, the nurse some suggestions, how could our nursing service be improved to provide a better service to the COPD

patient?

(.4)

14 Actually….the nurses to us, the patient really...ar…for us..ar…those ar…as such as such what kind of diet, instructing us in different aspects, it is very helpful indeed. Working on some other things, like the instruction in exercises are very helpful as well.

SL Dietary, exercises, the nurses can do something more in these aspects.

14 Very helpful…hehe.

SL Good good, anything else? According to the point of view of COPD patient, any other service that we can improve? You guys can give us some suggestions..

(.2)

8 Nowadays….different patients are having different situations, very hard to say!

SL I understand, just talk about it based on you, yourself=

8 =Meanwhile I'm comparatively more serious, different from those general cases, So, in the level 2 like us is preparing to go into level 3, I am the type which is comparatively serious, cause if the symptoms appeared, common family like us is taking care of us like this, sometime, when the symptoms appeared, there is really nothing more you can do, got to go to the hospital.

SL Umum…then how can the nurses be improved for those patients in a serious case?=

8 =The best would be…let those who are comparatively serious know more about the illness condition, we also know it. ..ar…on top of that, the nutrition, this is for sure, nutrition, doing exercises by myself, these things do….((for)) relieve our disease…ar, ar…and those aspect in terms of the hospital....it means, for example patient with the same situation said, meanwhile it seems like the the number of COPD patients is increased, Is the hospital enough? Is the hospital bed enough?

SL O, not enough hospital bed. I see I see, then what's your need personally? You have just emphasis that your situation is comparatively serious, how actually could the nursing service back up yourself, support you in terms of disease management? Any suggestions for us?=

8 =I am not quite sure about some medical physic ((physiology)), anyway the doctor advise us to take drugs, but now is not that often, since nowadays it is using

the more like using the spray, these are just help curing, spray directly into the lung and no need to pass through the stomach, there are quite a lot of drugs now, 4 of them, I have taken quite a lot, taken 4 different types=

SL =Then you have one opinion in terms of drugs…there are aspiration drugs which you don't have to take them orally, then apart from drug usage in the control of your condition, what could the nurses do in this aspect…

8 The most important to me now is the cough, I couldn't cough the phlegm up.

SL I see…the cough…the skills of coughing=

8 =The cough…sometimes sometimes got stuck in the chest, it seems like I couldn't cough the phlegm up, we can't really use the phlegm suctioning machine, sometimes my chest has such a situation, but not often, sometimes having a condition as such is a bit annoying, then I took some mucolytics, some doctors gave me some mucolytics, then I took the mucolytics under such a condition.

SL Then what about Ivan? Under the considerations of a COPD patient, what could be done by the nurses to respond to your need?

19 I think its sufficient now [SL It's sufficient already…I see] seems like I can feel it, maybe I have recovered a little bit better, not as serious as him (8), so I think it should be sufficient.

SL Sufficient in terms of which aspect?

19 (.2) I mean usually….I go to the hospital once every 2 months….for that, how do you call it….that [SL follow-up consultation?] follow-up consultation every 2 months, apart from that, I take care of myself usually.

SL I see…follow-up consultation every 2 months is sufficient, then mostly managing the condition in a self-care basis. What about the nurses? What about our nursing service?

19 Its quite good…like Nurse MN is quite considerate to us.

Q So the definition of good is having the considerations from the nurses…right…hahaha?

(Ha..ha..ha)

19 I think is quite good, take care of us well.

SL I see, like this, like this, it's because you have joined this workshop, right..is it

like this? Do you have this feeling?

19 Of course it is.

SL Then does this workshop is really what you guys needed?=

8 =It is needed, needed, at least, there is quite a lot of knowledge that we need to know, not everyone understands this disease [19 Yes, yes] at least some one should understand, meanwhile there are some skills, how to control the nutrition, how to manage during exacerbation and emergency situation, have some knowledge about this. [19 It means…it means the nurses….it means there is someone there introduce us of how to understand the illness condition, and how to adapt myself to the disease, it's quite good] At least I know what's going on, you know we know nothing about medicine.

SL Then you think this is what the nurses should do?

19 (.2) Not a must……

(8 : hahaha)

SL Not a must!?..<u>Why</u>?

19 Errrr……..if you dont…if you don't take care of yourself, it's useless no matter how good the nurses teach you.

SL I see…so you think that it is more like your own responsibility for taking care of your condition [19 Yes, myself] [8 hahaha] If there are any other suggestions, or Amy?

10 I think the same, just like, even if Nurse MN taught you, but you don't manage yourself, then it means nothing no matter how you are taught.

SL But do you think it is needed for Nurse MN to teach you?=

10 =Yes, the reason for need to be taught is to understand how…like we don't know what to do…how to, how to better help myself [8 that's more communication from the nurses, more communication] Thus, the nurse needs to..

SL I see…all of you think that the workshop is needed, it means what you want from the nurses is, to assist you guys to understand more about the disease, or skills for self-management for the disease, only work in the way would benefit to the management for the disease, right? Ok, I think it's quite complete for the content of our discussion, any more other opinions and suggestions regarding the self-management of COPD?=

19 =The origin of COPD…I think the main cause is smoking, right..right? It should be [8 Smoking is one of the reasons] For the situation as such, the government should do more promotion about quit smoking!

SL Tell smoker to quit smoking, tell them don't start smoking. It's good.. I see, right right. From the opinion of patient like you=

19 =Yes, now that after we got this condition…really…feel that smoking..really is something really bad really bad!

SL Really bad, really bad..

14 Smoking and taking alcohol is the worse, those who have this disease are mostly smokers [19 Feel that he (8) became so serious, can't even carry something, really is suffering]

SL Yes, yes.

8 Ya….I'm younger than he (19) [14 Smoking really ( )] I am not that old, he (19) is 10 years older than me, older than me for 10 years, the condition is still very good even older than me for 10 years, can tell by how he talks, his complexion [14 haha] my complexion is not good, showing…a bit not enough oxygen. In the past, I always think that my complexion is resulted from lack of oxygen=

SL =Just heard of what you guys said……like Ivan and Nick both mentioned the need for education from the government, about quit smoking, towards the community=

8 =It should, it should.

SL Its good, also should strengthen the consciousness of the high risk patients towards the disease, right… um, good good good. Anything else?

10 (.2) Should be quite complete.

SL quite complete.

8 Um…..more exchanging ideas, communicate more!

SL Right, then thank you everyone.

<u>Supplementary notes:</u>
Energy saving – forgot
Patting the neck with cold water – (8) tried for few times
It's not a problem of having much content, more content more knowledge.